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ABSTRACT

The report, over half of which consists of appendixes and lists of resources, discusses the educational and related life experiences of six disabled women. Focus is on their early experiences with school and family, their high school years, their college years, and their work. Their disabilities include blindness, osteogenesis imperfecta (fragile bones), paralysis, cerebral palsy, and deafness. Among the suggestions made to parents and educators are those involving the lack of positive images of disabled female children and adults in the community and in school books, films, and other media; the feelings of being treated differently than non-disabled children; the feelings of awkwardness, self-consciousness, and lack of self-confidence; and a lack of information about future career possibilities. Among the types of resources listed are groups, guides, periodicals, articles and books, and nonprint media. Included in the appendixes are a discussion of the Education for All Handicapped Children Act (P.L. 94-142), a discussion of the rights of the handicapped, and guidelines for the representation of handicapped persons in educational materials. A Women's Educational Equity Communications Network publications list is also provided. (DLS)

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WHAT HAPPENS AFTER SCHOOL? A STUDY OF DISABLED WOMEN AND EDUCATION

J.Corbett O'Toole and CeCe Weeks

1978

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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About the *Women's Educational Equity Communications Network*—WEECN is an information service and communication system established in 1977 and operated by the Far West Laboratory for the U.S. Office of Education under the auspices of the Women's Educational Equity Act. As an information service, WEECN collects, screens, classifies, stores, and provides information on projects and materials related to women's educational equity. As a communication system, WEECN facilitates contact among persons, groups and agencies who are working on behalf of women's educational equity. Users of WEECN include teachers, administrators, counselors, curriculum specialists, preservice and inservice trainers, researchers, students, parents, and citizens.

If you would like to know more about WEECN, please write to us.

—Matilda Butler, Director

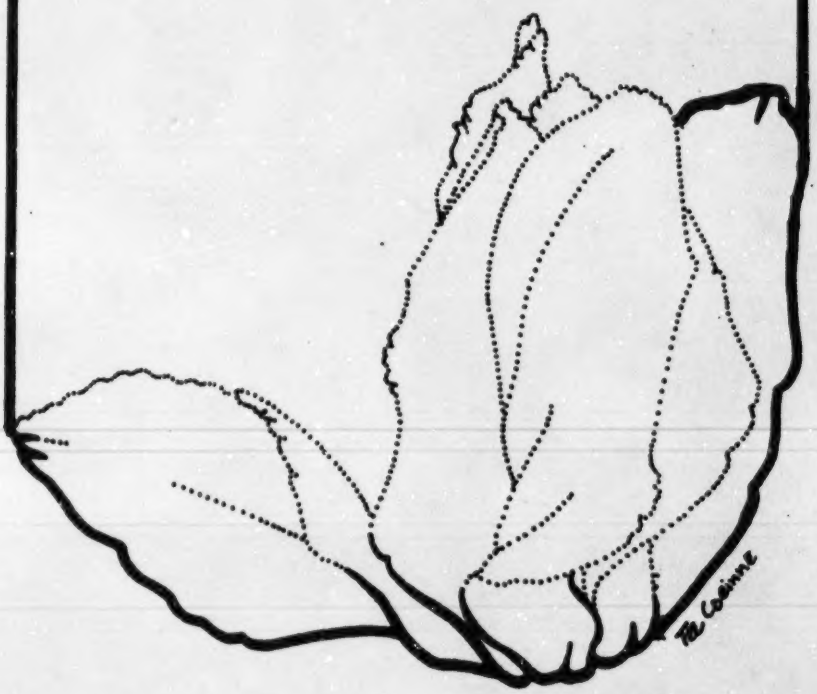
This publication, What Happens After School? A Study of Disabled Women and Education, has been submitted to the Library of Congress, Division of the Blind and Physically Handicapped in Washington, DC. It is hoped it will be available through their network of lending libraries throughout the United States for free use by visually-impaired and blind persons.

DEDICATION

To all of us,

for believing in ourselves

and surviving...



CeCe Weeks is Coordinator of the Welfare Advocacy Unit at the Center for Independent Living in Berkeley, CA. She is completing her master's degree in feminist therapy from Antioch College West. Her supervisor says that simplicity is one of her most outstanding characteristics.

J.Corbett O'Toole is a feminist and long-time advocate for disabled women. Disabled herself since infancy, she works as the Training Specialist with the KIDS Project at the Center for Independent Living and trains elementary school teachers and children to prepare them for the integration of disabled children into the regular classrooms. Formerly a nursery school teacher, she misses working with young children very much.

PREFACE

We are women. We are disabled. We are strong. These are the primary feelings one gets from listening to the women in this publication. The six women featured here vary in age. They are from different racial/ethnic backgrounds, economic groups, regions of the United States, and each has a different disability history. They have never met, yet a commonality of experience emerges as each woman describes her life in a unique way. Sometimes the stories flow from woman to woman, sometimes they juxtapose, sometimes they form contradictions. Collectively, they create an exciting mosaic.

Each woman speaks clearly about her feelings of isolation and differentness while she was growing up. She describes feeling unincluded in peer groups, racial groups, neighborhoods, and school settings. Yet these experiences have helped her grow and discover her strengths as a woman.

We, Corbett and CeCe, also have felt the intensity of being physically disabled and being women. We have both struggled, separately and together, to integrate who we are as women. Even today, we are still continuing to question and reaffirm our identities as disabled women.

For us, this self-discovery has often included sharing intimately our experiences with other disabled women. We have shared stories about our families, schools, and neighborhoods. We have exchanged lots of stories about doctors, teachers, friends, and lovers. These painful, funny, angry, and joyous stories have enabled us to understand, like the women in this publication, who we are as disabled women.

We hope you enjoy our insights. But, most importantly, we hope you profit from the powerful messages the six women in this publication offer to all of us.

J.Corbett O'Toole, CeCe Weeks
Berkeley, California
September 1978

ACKNOWLEDGMENTS

There are many people to thank for making this work possible. Rita Costick, our editor from the Women's Educational Equity Communications Network, has provided the supportive framework. Lynn Witt again demonstrated her strong commitment to disabled women by volunteering many valuable hours to edit. Evelyn Simpson also edited with a hand that would pride many an English professor. Deborah Hoffmann, Jane Scherr, and Betty Medsger contributed the beautiful photographs. Bronson West fed us plentifully at many and odd hours. Mary Lou Breslin, Judy Heumann, Lynn Witt, Sharon McLaughlin, Joyce Jackson, and Helen Jones provided initial input, a preliminary outline, and reviewed this work.

We would especially like to thank Darryl Benjamin, Jeanette Cordoni, and Elizabeth Greenberg for promptly and accurately typing our many revisions from the taped interviews and draft copies, and Sharon Taylor for designing and pasting up the final copy.

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INTRODUCTION

PUBLICATION DEVELOPMENT

The original idea for a publication on disabled women and educational opportunity was discussed by the Women's Educational Equity Communications Network (WEECN) staff and members of the WEECN Advisory Board early in December 1977. Preliminary research revealed very few materials existed which would assist disabled girls and women, their counselors and teachers, and other interested individuals concerned with educational opportunity and consequent career alternatives.

An ad hoc planning group of disabled women met with WEECN staff to begin development of the publication. Participants included: Mary Lou Breslin, Coordinator, and Lynn Witt, Administrative Assistant, Disabled Students Placement Program, University of California, Berkeley; Judy Heumann, Deputy Director, Center for Independent Living, Berkeley, California; Sharon McLaughlin, Program Coordinator, Division of Ambulatory and Community Medicine, San Francisco General Hospital, California; and Rita M. Costick, WEECN Editor. Helen Jones, WEECN Advisor and Program Administrator, Physically Limited Program, De Anza College, Cupertino, California also provided assistance in the development of the publication.

With the aid of these individuals, the publication authors were selected: CeCe Weeks and J. Corbett O'Toole -- activists for disabled women, members of the Disabled Women's Coalition of Berkeley, and employees in disability-related fields. The authors utilized their resource network of friends and co-workers and were able to identify several disabled women representing a wide range of personal experiences and lifestyles who were interested in describing their feelings about the educational process.

The development of the publication's resource list was greatly assisted by Lynn Witt and Mary Lou Breslin. Additionally, the authors, Helen Jones, and members of the ad hoc group mentioned above helped to identify relevant resource materials. This list presents only some of the existing resources. A more detailed resource list is in the process of being developed and will be available from WEECN in 1979. Suggestions for print, nonprint, and organizational resources for inclusion are welcomed.

Special thanks go to Helen Jones, Mary Lou Breslin, Lynn Witt, and Joyce Jackson, peer counselor at the Center for Independent Living in Berkeley; and to Dr. Patricia Morrissey, Educational Program Specialist, Bureau of Education for the Handicapped, US Department of Health, Education, and Welfare, for reviewing the document in draft form and making valuable suggestions for improvement.

PUBLICATION PURPOSE

The purpose of *What Happens After School? A Study of Disabled Women and Education,* is to provide insights into the educational and related life experiences of disabled women. Each woman highlighted in this booklet has shared honestly her feelings and realities about being disabled, and how her disability has influenced and directed the course of her life: past, present, and future. Specific issues pertinent to different levels of the educational process are discussed, including similarities and concerns common to many disabled women. Suggestions for educators and others interested in the positive educa-

tional development of disabled girls and women are noted. The resource list contains publications and other information relevant to disabled women and education.

This publication (including interview questions) was developed on the basis of what information would be most significant to the educational process and useful to other disabled girls and women, parents of disabled persons, and involved teachers, counselors, administrators, and others.

It is especially hoped that other disabled girls and women will value reading about women who have faced many of the same obstacles, fears, and frustrations because of their disabilities and yet have found they can learn and grow; develop personally, socially, and intellectually; and make choices for their lives just as many non-disabled women are more intentionally beginning to do.

Until recently, disabled women as well as non-disabled women have had to make it on their own. The supportive framework of concerned persons, the developing network of accessible individuals who collectively help one another is a growing phenomenon. Additionally, a new era of legislation -- benefitting women, minorities, and now disabled people -- has created new possibilities and alternatives previously unexplored by all but the most persistent and perservering. While this publication documents some of the problems indicative of an antiquated and individually isolating period in our history, the current positions of the women interviewed document their successes in dealing with the educational enterprise.

THE ROLE OF EDUCATORS

Although many people in the world of education may not yet have experienced teaching, counseling, or otherwise relating directly to disabled persons, the American Coalition of Citizens with Disabilities estimates that disabilities affect 36 million people -- one out of every six persons in the U.S.*

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*Noted in "Media Portrayals of Disabled People: A Study in Stereotypes" by Douglas Biklen and Robert Gobdan, Interracial Books for Children Bulletin, Volume 8, Nos. 6&7, 1977, p. 4.

With increasing emphasis on equality of opportunity for all people and the effects of legislation designed to provide disabled individuals open access to educational experiences, it is apparent that expanding numbers of educators will face for the first time disabled women and men, girls and boys in the classroom, on the playing field, in the library, and in the cafeteria.

It is hoped that this publication will stimulate serious thought about the important and pivotal role of educators working with disabled persons. If caring and sensitive to the problems and concerns of disabled individuals, educators have the potential to open up whole new worlds of independent living and learning, to enlarge rather than restrict human potential, and to create options and alternatives for disabled people.

Ann, one of the women interviewed for this publication, expresses her feelings about the importance of a particular high school teacher:

"Tenth grade terrified me to no end, but it was also a tremendous honor. I thought: 'Hey! These efforts haven't been in vain, someone does think that maybe you can hack it in this class.' The teacher we had turned out to be one of the best teachers I ever had. She worked us to the bone. She encouraged creative expression and cultural exposure. Largely through her many-pronged approach of helping us grow, I began to move out into other areas."

A college instructor also proved influential in Ann's life:

"I found a professor in speech pathology and audiology who was a key person in my development. He did not assess me as a blind person like many other professors did. He made me believe that I was being fully tested academically, personally, and professionally. This was very important for me. Whenever I looked for recommendations I went to this speech therapy professor because I felt he would honestly evaluate me."

DEFINITION OF TERMS

In this publication, the authors have chosen to use the term "disabled" as a positive reference to a physical or developmental condition. Lilly Bruck in ACCESS, The Guide to a Better Life for Disabled Americans* states:

"Disability and handicap are not identical in meaning. Except where it is unavoidable, I will use the term disabled and not handicapped to refer to physical, mental, sensory and emotional impairments that interfere with major tasks of daily living. The word handicap will be reserved for a unique use: to denote an interaction between a disability and an environment in which the design of the environment erects obstacles or barriers to disabled people. Thus, iron gates outside supermarkets and narrow checkout lanes within, designed to prevent shopping-cart theft, handicap people in wheelchairs by denying them convenient exit. Remove the gates, widen the lanes, eliminate the confining environment -- and the customer in a wheelchair, though still disabled, is no longer handicapped in access to the store."

--Rita M. Costick
WEECN Editor

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*ACCESS: A Guide to a Better Life for Disabled Americans by Lilly Bruck. New York: Random House, 1978, pp. 7&8.

WHO'S WHO:
THE WOMEN IN THIS PUBLICATION

"[After my accident,] I knew that even if I couldn't walk I wasn't going to be limited. I could still lead an independent life." Mary

Who are the disabled women in the United States? Where do they come from? What do they do? How have they been educated? How do they survive in the non-disabled world? Only recently have these questions been asked.

Overwhelmingly, the issue that disabled women most commonly identify as the major concern is the feeling of invisibility. With an estimated 36 million disabled people in the United States, why does each woman interviewed here describe much of her childhood as a period of intense isolation?

Many disabled women spend much of their lives in restrictive environments: special schools, institutions, hospitals, or with their families. Disabled women are often not visible around town, nor are they included in most public schools, workplaces, or social circles. Disabled people in the United States are a hidden population.

Comparative degrees of invisibility become apparent when the employment and training experiences of disabled women are contrasted with those of disabled men. The Rehabilitation Services Administration of the U.S. Department of Health, Education, and Welfare (HEW) reports the following information on women and men rehabilitated by state rehabilitation agencies in fiscal year 1976*: 1) Disabled men were more likely to receive vocational school and/or on-the-job training. 2) A higher percentage of disabled men (93.7%) were rehabilitated into wage earning occupations (versus 68.5% of the disabled women). 3) The average weekly earnings for disabled men at rehabilitation closure was significantly higher. Only 2.1% of the women, compared to 10.3% of the men, were earning $200 or more per week at closure. 4) The highest percentages of employed disabled men were located in a wider range of occupations; the highest percentages of employed disabled women clustered in fewer areas (i.e., services and clerical fields).

Those disabled women who do begin to look toward careers find few options. They soon discover that access to nontraditional women's roles is very difficult. And, more often than not, when disabled women do succeed in a nontraditional field, people are surprised by their accomplishments. Our society does not expect disabled men, much less disabled women, to become contributing members of American culture.

When disabled women do break through the invisibility barrier and attempt to live and work in the non-disabled world they often feel alone. Many disabled women attribute this to the absence of role models for disabled women. Again and again disabled women are defined primarily in terms of their disability; sex, race, economic background, and other factors are secondary. Consequently disabled women

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*"Selected Program-Related Characteristics of Men and Women Rehabilitated in Fiscal Year 1976." Information Memorandum RSA-IM-78, U.S. Department of HEW, Office of Human Development, Rehabilitation Services Administration, Washington, D.C. 20201, 11p.

are defined by what is perceived as lacking: physical normality, and not by who they are: women who happen to be disabled.

It is striking that although the disabled women interviewed for this publication represent a wide range of experiences, most feel that their primary identification by others in the world is based on their disability. Often this identification does not make room for individual women's skills and interests. And yet, the women presented here have struggled to survive and to define themselves; and each has done so in her own way. Individually, they tell interesting stories, collectively they reflect the struggles and strengths of a new wave of disabled women.

Ann

Ann was born and raised in Honolulu, Hawaii. Of Japanese ancestry, she is 34 years old, married, and has two daughters aged eight and two. She currently works as a counselor for KOKUA, a program for disabled students at the University of Hawaii.

Ann has been legally blind since age seven when she underwent a period of severe illness. After her illness, she continued to attend the same elementary school but fell behind in her studies because her vision was becoming progressively worse. She attended a junior high school with a special resource program for blind students where learning was facilitated by large-print material. In ninth grade she began using a magnifying machine that allowed her to flourish academically for the first time in her life.

Graduating from high school in 1962, Ann was eighth in a class of 800. In college, she studied speech pathology and audiology and received her B.A. degree from the University of Hawaii in 1966. A year later she began work on a master's degree in social work which she completed in 1969, also at the University of Hawaii.

Joanne

Joanne, 43, lives in Albany, California with her husband and two daughters aged nine and ten. She teaches sign language to hearing people and is coordinator of Deaf Services at the Center for Independent Living in Berkeley, California.

Joanne's parents immigrated to the United States from Hungary at the beginning of World War I. She was born severely hard of hearing. She grew up in the Flushing section of New York City and has one older brother. Joanne attended a school for the deaf until the ninth grade when her parents encouraged her to attend regular high school. This school did not provide interpreters for the deaf or supportive services. The psychologist at her former school encouraged her to apply to Gallaudet College, the only liberal arts college for the deaf in the world.

After graduating from Gallaudet, Joanne began teaching at a state school for the deaf. She then moved to San Francisco and worked as an IBM tab operator at the

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Naval Supply Center. Later, she became the first deaf teacher hired by the San Francisco Unified School District. She taught deaf children for 14 years in many schools from pre-school to junior high, and also taught emotionally disturbed deaf children in San Mateo, California.

Nicci

Kathleen Nicole-Rose (Nicci) is 21 years old and has osteogenesis imperfecta (fragile bones). Nicci started college in August 1974 and is a full-time student studying psychology at the University of Illinois. She is actively involved in women's issues, is woman-identified, and is currently looking for a job.

Nicci grew up on the south side of Chicago, the youngest child in her family and the only girl. Her mother is white and her father is black. She has four white brothers, three of whom have the same disability as she. Due to her disability, as a child she broke bones in her legs approximately 40 times as well as bones in other parts of her body.

Nicci attended special schools, graduating from Spalding High School, a school serving both mentally and physically disabled in Chicago. Until age 17 she used a wheelchair to get around but now uses a cane. She was president of her high school graduating class.

Alice

Born prematurely, Alice was placed in an incubator and was totally blinded by oxygen burning her eyes. Today, at 26, she has just completed her B.A. degree in sociology at Hunter College, and wants to become a rehabilitation counselor to help other disabled people. Active in her community, she does volunteer work for "Help Line" as a telephone friend for senior citizens. She belongs to the Community Board in her neighborhood helping others deal with problems of welfare, home attendants, home care, and related concerns. Active in civil rights organizations which attempt to improve conditions for disabled people, she belongs to Disabled in Action and the American Council of the Blind.

Alice is Puerto Rican and grew up in Brooklyn, New York. She attended special classes for the blind in New York City public schools. In junior high school and high school she attended regular classes with one or two periods of special classes for blind students. As a child, she felt isolated and her neighborhood afforded few recreational activities. Fortunately, during her teenage years, The Lighthouse for the Blind provided her with an opportunity for social interaction and recreation.

Mary

Mary was born in St. Paul, Minnesota in 1947 and moved to Seattle four months later where she grew up and attended public school. The oldest of eight children, Mary has three brothers and four sisters. She says her half-Chippewa father has been the greatest influence upon her life.

After majoring in history with a minor in math she graduated from Seattle University in 1970 with a B.A. in education. After teaching for two years at St. Mary's Mission School on the Colville Indian Reservation in Washington state, she worked for a year as a counselor intern at St. Mary's while attending graduate school. After receiving her master's degree in guidance counseling in 1973 through the University of South Dakota's Center Satellite Program, Mary was hired as a counselor at St. Francis Indian School in Saint Francis, South Dakota.

In 1974, Mary broke her back in an automobile accident. This left her legs permanently paralyzed, forcing her to rely upon a wheelchair. She had been a counselor at St. Francis for over a year before her accident and returned to her job after a year's leave of absence. A wheelchair ramp was built to the classrooms so she could continue her work. Each winter she shovels the snow off the ramp of her home, a trailer in which she has lived by herself for the past two years.

After her injury, Mary also resumed the role of scorekeeper for the varsity basketball team at her school. Says Mary, "I wanted to continue doing the things I had done before. It was just natural to continue keeping score."

In addition to working full-time Mary is also involved in several organizations and outside activities. In 1977 she was elected secretary of a disability rights group called Handicapped Citizens of South Dakota. She went to Houston for the National Women's Conference and worked with the Native American Women's Caucus, and the Disabled Women's Caucus. She has gone to Washington, D.C. to meet the President as a representative of both disabled women and Native American women. Mary has been on the Board of Directors for South Dakota Indian Counselors Association since its creation in 1974, and currently serves as Secretary/Treasurer. Mary is also involved in a women's group on the Rosebud Indian Reservation which includes both Indians and non-Indians, called White Buffalo Calf Women's Society, and is a member of the South Dakota Indian Education Association and the National Indian Education Association.

Debbie

Born with cerebral palsy, Debbie is 19 years old and a recent high school graduate. She will soon begin studying special education in a paraprofessional program at a local community college, desiring to work with physically disabled nursery school students. Active in wheelchair sports, she often places at the top in competition, and would like to continue her career as an athlete. Debbie is of black and American Indian parentage, and lives with her mother in Emeryville, California.

Growing up in Oakland, California, Debbie attended Catholic school until the sixth grade where there were no special programs for disabled students. She and her four brothers and one sister were the only black students. After attending public school for a time, Debbie quit in the seventh grade because non-disabled students teased her and because she felt her teachers were not sensitive to her disability. She stayed out of school for two years, but had a homebound teacher. The next year she underwent several operations which were intended to straighten out the muscles in her ankles, legs, and hips. When she was ready to go back to school, she attended a school for the physically disabled which had a cooperative mainstreaming program in a regular high school. In her senior year she began attending an integrated regular high school as a full-time student.

EARLY EXPERIENCES WITH SCHOOL AND FAMILY

"What do I want from all schools?
High energy....understanding....compassion....maternal love." Joanne

For all children, elementary school often serves as the first introduction into the mainstream of American culture. The schools transmit the basic cultural values through books, the academic structure, and attitudes. These values have often excluded disabled people from the cultural mainstream. Many disabled girls find the elementary school years to be extremely isolating. They sense and observe differences in how adults treat them and how they treat non-disabled children. Many disabled persons mention feeling uncomfortable with this difference in interactions.

Although the feeling of difference is clearly present, in these gradeschool years it is often poorly articulated. This feeling of difference is often internalized; women in reflecting upon these early years mention feelings of frustration, awkwardness, ugliness, self-consciousness, and ignorance. When searching for the basis of these feelings, we find disabled women most often mention two factors: the absence of adult disabled women role models and the inability of non-disabled adults to articulate their own feelings about disability. These factors become critical as disabled women discuss their personal development while going through school.

Without the presence of successful disabled women, disabled girls often have difficulty in identifying who or what they can become. This problem is intensified by the lack of positive images of disabled women in books, on television, in films, as well as in schools. A message begins to emerge: there is no role for disabled women. Schools end up, knowingly or not, conveying this message.

The overall impressions of elementary school described by the women interviewed here are twofold. On the one hand, they felt the education they received was adequate academically; on the other hand, they found the schools' staffs did not provide sufficient emotional support concerning disability.

Joanne begins by talking about her family's reaction to her disability and her first school experiences:

"My parents were born in Hungary and were forced out of Europe at the time of the First World War, and came to America. They met in New York and decided to get married. The doctors warned them that they might have handicapped children because they were first-cousins. Their first child was born normal so they thought they could have other healthy children, but I was born handicapped.

"When I was a baby my parents were not aware of my hearing problem but they were aware of my being somehow different from other children. They sent me to countless doctors trying to find out what was wrong with me. The doctors gave them bad diagnoses, saying that I had a behavioral problem or that I was mentally retarded. My parents did not find out I was severely hard of hearing until I was four-and-a-half-years old.

"After my parents found out what was wrong with me they sent me to a residential school for deaf children. I remember my first day in school feeling separated from my family and depressed for the first time. But in a number of weeks I felt comfortable at school making friends with deaf peers." *Joanne*

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Ann describes her experience of losing her vision:

"I am legally blind. I was in second grade when my poor vision was detected following a period of illness. I went through the regular school program until the sixth grade. The print kept getting smaller and smaller; consequently, the blackboard became less and less manageable. My teachers passed me on through elementary school because no one else knew what to do with me." *Ann*

Nicci, Ann, Debbie, and Joanne discuss their childhood school experiences:

"Grammer school was good academically. They taught us reading, writing, and arithmetic -- but we never had any freedom in school. I never liked the fact that they separated us from everyone else. I lived in a neighborhood where my activities took place on the street -- we didn't have church activities. The school was very over-protective of me because I had osteogenesis imperfecta (fragile bones). My mother, however, was never over-protective. She let me play softball and do anything physical that I wanted." *Nicci*

"In eighth grade we began career preparation activities. I thought that about all I could do was be a telephone operator. Then to my dismay, I was told: 'You can't be an operator because you can't see the dials light up to press the right numbers. The telephone company will absolutely not hire you.' I had a very child-like concept of what I could do until the ninth grade." *Ann*

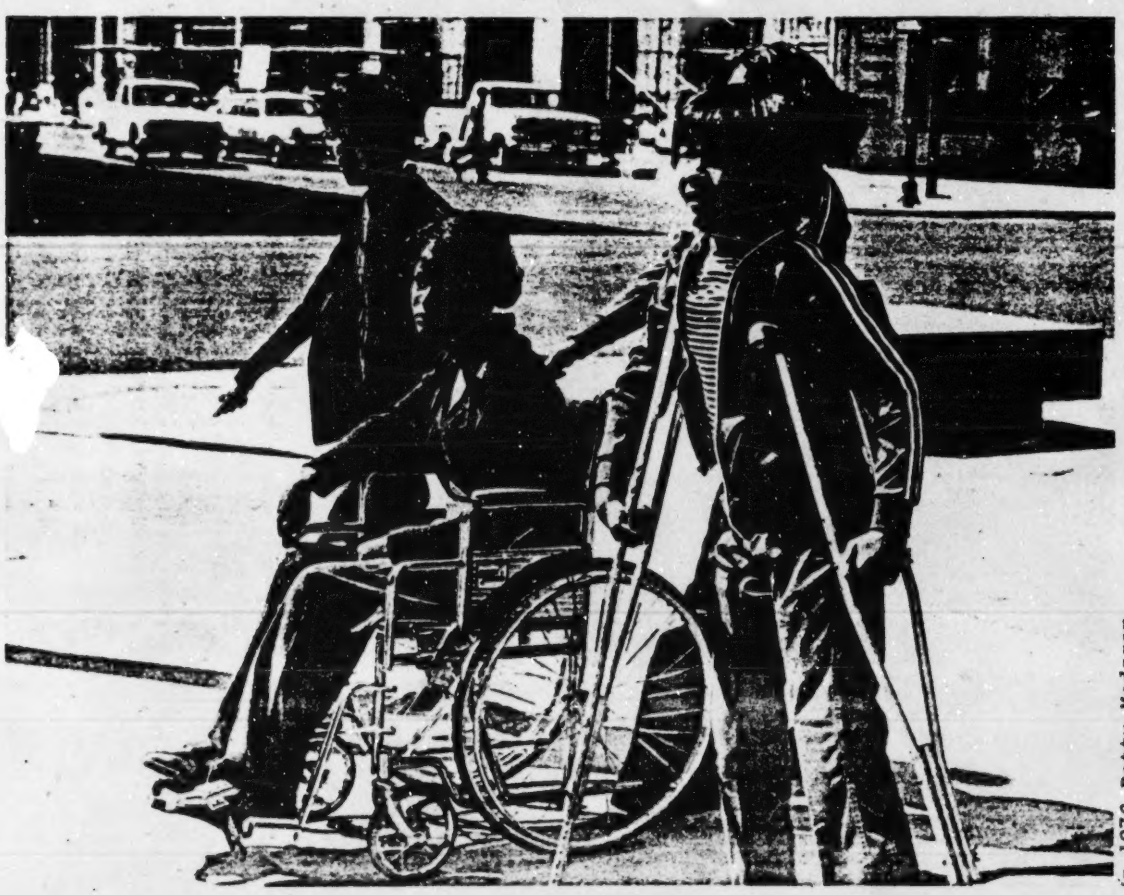
"I started out in Catholic school and went there until sixth grade. There were no other disabled kids in the school and we were the only black family. Catholic school was tough; my teachers didn't understand me. I couldn't learn as fast as the other kids but they kept pushing me anyway. It was hard on me getting bad grades. I could do the work but it took me longer than the other students. So my teachers just passed me on through." *Debbie*

"My school put too much stress on speech and language development. Other academic courses like history and geography were emphasized only enough to make the school look good. I was a prize pupil there because I was able to speak more clearly than most students. Visitors to the school were brought into my class and were impressed by the kids who could hear somewhat. The really deaf kids were completely ignored...The school was for deaf girls and every employee was a woman, except the head of the school. I felt very close to two teachers who were sensitive to the needs of the kids. They both had deaf relatives and could communicate easily with me.

"I spent the first ten years at the school feeling frustrated about the education I was receiving. I was always ahead of the other deaf children because of my being severely hard of hearing instead of completely deaf, but I was held back because the teachers made no distinction between my disability and that of other deaf kids. Consequently I lost a lot of valuable time in school." *Joanne*

Many disabled women have noted the difficulty they have had with attempting to acquire a positive self-image. Debbie addresses this issue:

"I like sports and in the summer I like to rest. I played on the Catholic school volleyball team, which was good for me because there wasn't much running around involved. I became interested in sports in fifth grade. I liked to watch my brothers play football. In junior high school I started playing wheelchair sports. The only time I had ever been in a wheelchair was in the hospital. I thought that was the only place they belonged. My sister and I started racing through the hospital hallways. I really liked it because I could never move that fast before. Sports have helped me to gain confidence in myself. Confidence was something I had lost a long time before." *Debbie*



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Alice discusses the topic of disability from a grade school perspective:

"In g.ade school the subject of disability was "hush-hush". We kids didn't have any support groups or space to discuss disability. No one ever told us anything. Whenever we asked questions about disability they usually went unanswered. They either evaded the subject or gave us wishy-washy answers. We never got a chance to talk with anyone about our feelings...It was frustrating because I wanted people to tell me the truth about what my life was going to be like when I was 18 or 20 years old with no one taking care of me." *Alice*

Ann discusses her need to learn and grow during the elementary years:

"My parents valued education very much. I never could do that well in elementary school...but I wanted to learn; I wanted to know things; I wanted to be part of the school. The teachers tried very hard to involve me in what I could do. That was really great. I was involved in drama, music, and hula dancing. I learned hula dancing which is a religious type of expression and a beautiful reflection of the respect that the Hawaiians have for life. The love in the dance, the openness, the reaching out, the giving and taking is really beautiful. I wasn't the best student in the world, but I guess I had other ways of contributing and belonging." *Ann*

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The early years in the educational system formulate the base for years of education to come. This foundation needs to be positive and nurturing so that it can provide experiences which produce healthy self-esteem and self-confidence.

- Disabled (as non-disabled) children need opportunities to develop strengths and learn about their capabilities.
- Interaction with peers, making friends, sharing, and being accepted by others are critical to self-acceptance.

HIGH SCHOOL

"They tell us we're special, but they treat us like we're different." Nicci

High school often functions as a role play of, and preparation for, adult life. It is the last stop in mandatory education. High school informally teaches the rules of social interaction while attempting to ready students for the "real world."

It is in high school that the reality of society's attitudes toward disabled women begins to crystallize. Society provides few clear role models for disabled women; many high school staff have found it difficult to prepare such women for an independent future.

Disabled women may begin to find that their special school academic curricula are inferior to the curricula of their non-disabled counterparts. Additionally, school staffs have often had low expectations for their disabled students and many students feel restricted in social interactions within the schools.

Disabled women are now becoming very concerned with the question, "What happens after high school?" Parents are often uninformed, and rely on the schools for guidance; high school teachers and counselors are often just as unaware of the options available. Women fear that they have been prepared for nothing more than returning to their parents' home or to institutions.

It is also during high school that disabled women begin to become more articulate about

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their needs. It is a critical time. All the women interviewed discussed feelings of anger at the inequities in society in general, focusing on schools in particular.

Anger then becomes a motivating force for survival. Disabled women may use anger in different ways; it can be used to define for themselves what they want from schools. This knowledge of individual needs and wants forms the basis for future self-definition.

Debbie talks about her experiences in a mainstreaming program:

"For three years I went to a school that had a mainstreaming program. At first, none of the classes was accessible. That created a problem for me. But now there are ramps to every classroom. In my senior year, I started going to regular classes full time. I liked the teachers but sometimes the students teased me because I could not walk well. Still I learned a lot and feel pretty satisfied about the education I got. Before mainstreaming, I didn't think I could accomplish anything. I thought I'd be sitting around all my life. I would think my problem came from being disabled, being a woman, and being black. But mainstreaming changed my life. The school encouraged us to do what we could and make the best of it." *Debbie*

Nicci, Alice, Ann, and Debbie provide recollections of how they viewed their high school experience and how they were seen by the students and staff of their high schools.

"I survived high school because I realized the situation that was happening. The school tried to make us feel different. It was like they were saying: 'Don't expect too much because you're crippled. Don't expect anything for yourself after high school.' They weren't career oriented. They never tried to prepare us for what would come after high school. I never thought I would be living away from my mother. The school held the view that independent living was simply out of the question." *Nicci*

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"In high school, people judged me because of my disability and that was where I had the most problems. People didn't see me as a Puerto Rican or a woman, they saw me as a blind person. If I hadn't been disabled, school would have been a lot easier. I would have gotten a better education if I had not been disabled. The resource teachers didn't really try to teach us. They felt they could pass us on letting us get away with minimum work instead of making us meet the same standards that non-disabled children had to meet. As a result, when I graduated from high school and wanted to go to college, I wasn't prepared; I had to take remedial courses. If it weren't for the Lighthouse for the Blind, I would have never made it." *Alice*

"High school was a school for the mentally and physically disabled. They segregated us so we wouldn't be ridiculed by regular high school students. Yet, we had our own divisions in high school. The people that limped were better than the people on crutches. The people on crutches were better than the people in wheelchairs. And the only way that someone in a wheelchair was better than anyone else was if they had clear speech. If a kid had cerebral palsy and couldn't speak clearly, it didn't make any difference if she had an I.Q. of 2000. It wasn't being grouped together with disabled kids that affected me, it was the absence of non-disabled kids." *Nicci*

"I remember interacting in school with other kids who were disabled, kids who had clubfoot or were severely bowlegged. We were all the butt of everyone's ridicule and exclusion. There was a comraderie among us because we were mutually hurt. I suppose that's had an influence on my life." *Ann*

"When I returned to school, I went to Cameron, a school for physically disabled kids. It was the first time I had ever enjoyed school. They tested me and I started working at my own level and began catching up on things I had missed. It was a small school, and everyone knew everyone. It was more like a family instead of a school." *Debbie*

"One friend with whom I graduated is really smart. He is amazing. If I had any questions about school I would go to him because he was so far ahead of everyone else. He was at the top of the class in high school. He kept telling me: 'You can do it, this is easy.' And I did." *Debbie*

Joanne and Ann discuss the importance of appropriate educational services and equipment.

"I went to a private high school for Jewish kids for one year. It provided no interpreter services and no tutoring which was a necessity for me if I were to keep up with the hearing students. At the end of the school year, I told my father not to waste his money on private tuition." *Joanne*

"It wasn't until ninth grade (the tumult of adolescence) that I began putting together what I was, how I was different, and really coming to grips with the fact that I was not the same as other people. I desperately needed to prove to myself that despite the difference there was really something of value in my being alive...The school had a magnifying device and for the first time in my life I was able to read printed material. Prior to that I was just cruising, making it from year to year without learning much of what was intended to be learned in the classroom. My mind had been in a vacuum in terms of academic learning until I got that reading machine. Everything was new, everything was exciting, everything was challenging to the point of sometimes being overwhelming. It was an incredible door..." *Ann*

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Several ideas stand out as we review comments for the high school years:

- Early career education and planning is critical to develop independence and positive feelings about the ability to take care of ourselves while involved in work that is also personally satisfying.
- Appropriate materials, equipment, and services are critical to the educational success of disabled students.
- To lessen feelings of difference and to achieve educational equality, academic and social standards must be consistent for disabled and non-disabled students, whether integrated or not.

COLLEGE YEARS

"The only reason I get the things I want is because I go out there and fight for them." Alice

For those disabled women who attend college the world opens up. Perhaps for the first time they are exposed to an active, vibrant, intellectual community. Many disabled women get their first sense of real accomplishment in college.

College often functions as a proving ground for disabled women. If a woman can get through this, then the door to independent living is permanently opened. Women start to experience, not just imagine, what it is to work, live on their own, and have an independent life. They may realize that not only have they been limited in knowledge about their real options for the future, but that many disabled kids behind them are still being restricted in the development of their own potentials.

Many disabled women feel a sense of commitment to each other, choosing "helping" professions, with goals focused on entering the professions and changing attitudes about disability. How much this is felt is often based on the age when the woman became disabled. Women who become disabled later in life often wish to pursue previously chosen career directions.

During the college years, women begin to clarify their individual definitions, of themselves, their careers, and other relationships. Many disabled women still feel discrimination based on disability, and frustration at how far behind they are -- both academically and socially. But, perhaps for the first time, we begin to sense that these women are succeeding.

For Joanne and Alice, college was a place of academic and social acceptance:

"At Gallaudet I did not feel different from the other students. There were students who were hard-of-hearing, deafened, and deaf. Finally I found my identity. I could communicate with them on a very equal level. I learned American sign-language in six months. I felt a lot better about myself and I grew tremendously. I grew up a great deal when I went to college and got a lot of feedback from people who became deaf at a late age. From these people I learned how to communicate. Most deaf people never have that opportunity." *Joanne*

"In college the education is better and teachers see you as more of a person. You're more on your own--it's a whole different ballgame. Teachers feel that if a disabled person gets all the way to college she must have some abilities; they can work with her." *Alice*

Alice and Nicci have disabilities which are not immediately obvious. Yet, they too felt the impact of disability in their college years:

"I was a super odd-ball bookworm. Some people thought I was snobbish until they realized I couldn't see because I didn't wave to them across the street. I didn't even know they were waving to me. When they smiled at me I didn't smile back. Once they realized that I couldn't see, they started saying hello. Others just avoided me altogether because they didn't know quite what to do or say." *Alice*

"I stopped using my wheelchair when I entered college. I had always used it at home. One day, I was walking around campus. My leg hurt so I was using my crutches. People said, 'Oh, what happened to you? Did you hurt your leg?' I'd say, 'No, I'm handicapped.' Then they laughed and patted me on the back like I was saying a big joke." *Nicci*

Alice and Debbie speak about their college experiences:

"When I first went to Hunter College in New York City I found out that the education department was very hard to get into if you have a disability. So I decided I would become a rehabilitation counselor so I could help other disabled adults. In college I became active in the Disability Rights Movement and then I started getting support from the disabled community.

"College teachers are willing to exchange ideas and ask questions about disability, but they never get into their personal feelings. They are usually willing to make accomodations for me like letting me tape a lecture or reading out loud what they write on the blackboard. I'm willing to meet them half way and make my own adjustments if they're willing to make accomodations.

"I had one teacher who wouldn't let me tape his classes. I tape all my classes. I told him he was in violation of Section 504* and that I would pursue it with a college lawyer. 'I know my rights and I use them when I need to and if you want to discuss this further I will arrange an appointment,' I said. He said: 'No, it's okay. You can tape it.' At the end of the semester he said: 'I've enjoyed having you as a student.' *Alice*

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*Section 504 of the 1973 Rehabilitation Act (Public Law 93-112), as amended in 1974 (PL 93-516), is entitled "Nondiscrimination Under Federal Grants" and states: "No otherwise qualified handicapped individual in the United States shall, solely on the basis of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal assistance." See Appendix for further information.

"I know some kids who dropped our of school, some who are struggling to barely make it, and some who don't care if they learn anything or not." *Debbie*

Ann describes her reasons for returning to graduate school:

"After I got my B.A. degree in speech I realized I did not want to correct people's lisps. I did not want to help a stutterer not stutter. I did not care to work with non-verbal people because being blind I depended upon verbal responses to know what people were feeling. At that point I was very verbally dependent. When aphasic (speech impaired) and deaf people came in, I found I couldn't cope. So, I decided to get my graduate degree in social work." *Ann*

Visible numbers of disabled women have only recently been seen on college campuses. It is important to recognize that disabled women face the same concerns and problems related to the college years as do non-disabled women.

- Classrooms and class procedures may need to be altered to adequately accommodate disabled persons.
- Acceptance and understanding of disability by peers and others is critical.
- Disabled women need access to all the campus services and activities open to non-disabled women.
- Career counselors can provide innovative counseling to help each disabled woman explore the many career opportunities open to her.

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WORK

"I'm here to help people develop their full potential as human beings. I help them move toward whatever they feel is appropriate and whatever might be of value." Ann

The issues concerning disabled women and work are not simple. While national statistics are available concerning how much money men make versus women, how much money non-white men make compared to white men, and what percentage of women are in a given field, no such comparable information is available concerning disabled women. What information that does exist has been gathered only through small, primarily independent counseling and placement programs, and the various state departments of vocational rehabilitation. And even this information cannot be considered representative of the disabled population in the United States; many disabled job seekers are not aware of, or choose not to use, the services that are available to the disabled job seeker. It is obviously simple to survey a business to determine the ratio of men to women, or white to non-white employees. However, trying to determine who among this group are physically disabled is not as easy. Many persons in the work force are disabled; but, for a large percentage of these individuals, their disabilities are not obvious. A person with a "hidden disability," such as a vision impairment or epilepsy, may be unnoticed as being disabled.

Although job opportunities for disabled people are beginning to change with the implementation of the Rehabilitation Act* which mandates employers receiving federal funds not to discriminate against disabled job applicants, changes in attitudes toward the disabled job seeker have a long way to go. There are still many myths and pre-conceived notions about the abilities of disabled individuals that need to be re-examined before these individuals will become an integral segment of the work force.

While the tendency of an employer to see the disability first, and the qualifications and skills of the person second, applies to both women and men who are seeking employment, the disabled woman faces additional obstacles when looking for a job. Often, women who grow up disabled are not expected by their families to obtain employment after completing their education. Additionally, many of the jobs traditionally open to women--teaching, nursing, clerical positions--are often closed to disabled women.

As has often been the case with non-white women, disabled women have been traditionally employed in stereotypic job categories. For years, employment for non-white women was available only in low-paying, semi-skilled positions, with low public visibility. Even today, with affirmative action legislation mandating equal access to employment for all women and minorities, non-white women still make less money than their male and/or white counterparts in the same job. For disabled women, the situation is equally poor. According to the 1970 U.S. Census, 76% of all disabled women are not employed. In addition, even the stereotypical positions available to disabled women are extremely limited. Unlike their non-white sisters, disabled women face discrimination not on the basis of race, but on the basis of type of disability. For example, blind women may be seen as able to do only one or two jobs and may be channeled into positions as

*Refers to the 1973 Rehabilitation Act (Public Law 93-112), as amended in 1974 (PL93-516).

dictaphone typists or teachers of the blind, regardless of their other interests or abilities.

The vast majority of disabled women in the United States are unskilled after 12 years of public education, able to identify few career options, and society as a whole remains unaware of their existence. If 76% of disabled women are unemployed, then 24% are employed. Partially due to the Rehabilitation Act of 1973 and the women's movement, however, disabled women are becoming more visible. Many are now breaking into fields that previously were reserved for able-bodied men. Disabled women are employed as investigators for the Office of Civil Rights, program directors, architects, rehabilitation counselors, community organizers, and computer programmers. These few examples show there is a tremendous potential in the strengths and abilities of disabled women.

Debbie and Joanne currently work with disabled individuals.

"I'm out of high school now. I'm going to study special education in college. I hope to work in nursery schools with disabled kids. I will be working at the Berkeley Outreach Recreation Program for the Disabled, helping to plan recreational activities and wilderness trips for disabled kids." *Debbie*

"Ever since I was about ten, I thought I might be a teacher of the deaf. My teachers would send me to other classes to help teach their students. I felt I had a natural teaching power within me. One day I was being interviewed by a teacher and she asked what I wanted to do when I grew up. I said, 'I want to be a teacher like you.' She said I couldn't be a teacher; no deaf person could be a teacher. My world then fell on me. I had no more desire to teach deaf kids until I went to Gallaudet College. There I learned I had an opportunity to teach.

"I was the first deaf teacher hired in the San Francisco Unified School District. I spent fourteen years teaching in many different schools from the pre-school level to junior high. Later I moved to San Mateo, California, where I taught a small class of emotionally-disturbed deaf children. I worked well with these kids, and I taught them to communicate effectively, but I was laid off a year later due to a big slash in the Special School budget. I felt it was time to seek a different way of life." *Joanne*

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"My hearing friends and some deaf friends have given me much support. When I realized I was no longer a teacher I felt angry and helpless but my friends encouraged me to keep my chin up. So I switched from teaching deaf kids to teaching sign-language to hearing people. This has given me a better insight into myself." *Joanne*

Mary discusses the impact of becoming disabled later in life and the effects on her work life.

"After finishing my master's degree, I applied at St. Francis Indian School in St. Francis, South Dakota, and was hired as a tutor/counselor. I've been working here five years. The first year I worked with students who were having difficulty with reading and math. The second year I was hired as a counselor in a drop-out prevention program designed to help kids who were behind catch up and students who had dropped out who wanted to come back. It was during my second year that I had an automobile accident which broke my back and paralyzed my legs.

"When I was in the hospital, I didn't have a counselor. They sent a psychologist to see me once and I refused to talk to him. I did not like his approach. But my doctor was straight forward and very honest with me the whole time. He never talked as though I would be limited. I felt shocked and depressed and I didn't realize the permanency of my disability.

"When I did realize it I cried a lot and was really upset. I was always thinking about when I would get out of the hospital, always hoping that I would be able to walk again. But I knew that even if I couldn't walk, I could still drive a car; I could still go back to work.

"When I did go back to work very few of the kids said anything at first. They would wait awhile and then maybe ask questions. Sometimes there's a different kind of feeling I get from Indian students than from non-Indian people. Indian students will ask if you need help and if you say no they are more likely to stand back and let you struggle. Non-Indian people are more impatient. Kids are still at the stage where they're constantly learning new things; it takes them awhile to catch on to things. They don't like adults rushing up and helping them. Like when you see a little kid struggling with tying his shoe maybe you just want to go over and tie it for him, but he wants to tie it himself. It's the same with me when I'm struggling to get my wheelchair out of the car. Able-bodied adults are quick to react. They have to be right there--and a lot of times their help makes it harder. A disabled person gets feeling dependent because others are always trying to help. It makes you feel like your independence isn't valued.

"My doctor wanted to hire me to work as a liaison between the patients and the hospital staff. He felt I had a natural ability to communicate and relate to people. This stems from confrontations I would have with the staff demanding my rights and my dignity. Just because I'm disabled doesn't mean I'm going to work with disabled people. First of all, I'm an Indian counselor and that's where I choose to stay. I think that will be true for quite some time. If I chose to work with disabled Indians they would have to come into the regular school system. I would not go into a special program." *Mary*

As a disabled woman, Ann feels she has much to offer other disabled people:

"I work at the University of Hawaii in the KOKUA program. The word 'kokua' is a Hawaiian word meaning 'help'. I came to work here in January of 1967, the spring term before I began graduate school. After I received my graduate degree in 1969, I began full-time employment. I work as a counselor for disabled students, providing them with whatever they need to off-set their disabilities and giving them the opportunity to secure the kind of college education they want.

"We see people as very separate and unique in themselves. Wherever they happen to be in their lives and whoever they are is fine. I'm not here to impose anything on them; we work with relationships of mutual respect. It's been very challenging, certainly it's been overwhelming at times, but it's been exceedingly stimulating and growth-promoting for me to work with 'people-problems.'" *Ann*

"I'm very happy I'm a woman. Disabled women have a peculiar opportunity to find ourselves and to sink into life more fully--to share that with other people, people whom we love and who love us.

"If I am to be admired for my achievements I don't want it to be out of pity just because I am blind. I would rather be admired because I am a decent person who just happens to be blind. I feel quite strongly in my old age that I did what I did because I had to do it for myself. Being blind I had to do it." *Ann*

The women in this publication consider gainful employment to be an expected, integral part of their lives. Indeed, work (paid or not) is a significant part of most people's lives. Mary provides an important model as she demonstrates that life and work can go on even after a life-altering accident.

- Many persons who are disabled in adulthood can resume their former work with appropriate adaptations in the work place and in personal routine or schedule. But employers and co-workers must prepare to facilitate the disabled worker's return.

- Personal achievements based on individual ability and skill are important to all women -- non-disabled or disabled. Few people want to be singled out for unwarranted praise because of their sex, race, or disability.

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Lack of Positive Images of Disabled Female Children and Adults In the Community and in School Books, Films, and Other Media

o Avoid negative stereotypes of disabled persons. An important article entitled "Media Portrayal of Disabled People: A Study in Stereotypes"* outlines negative portrayals to be eliminated:

1. The disabled person as pitiable and pathetic.
2. The disabled person as object of violence.
3. The disabled person as sinister and/or evil.
4. The disabled person as "atmosphere"; e.g., blind musicians, newsdealers, and the 'blind man with a cup.'
5. The disabled person as "Super Crip..." (emphasizing) the extraordinary achievements of disabled persons who 'overcome' -- thus becoming a credit to their 'race.'
6. The disabled person as laughable.
7. The disabled person as his/her own worst -- and only -- enemy.
8. The disabled person as burden.
9. The disabled person as non-sexual.
10. The disabled person as incapable of fully participating in everyday life.

• Introduce positive images of disabled women and men, girls and boys. Find pictures, posters, and other media that show people with disabilities achieving. Provide real-life role models by inviting other disabled persons to the classroom, home, or community center to talk with both disabled and non-disabled children and adults. Find disabled women in the community (or nearby area) with careers, with families or as single individuals, with various activities/interests and provide an avenue for them to share with others. The experience of first-hand interaction is more powerful than books. "Seeing is believing" -- an important message for young people and adults uncertain about their own futures.

Feelings of Awkwardness, Self-Consciousness, Lack of Self-Confidence

• Build self-confidence and comfort with self by providing opportunities for new skills to be learned -- dance, basketball, swimming, mime, drama.

• Provide success experiences to develop self-confidence, self-esteem, and a positive self-image, and to create successful individuals capable (and eager for) new challenges. Women, especially, have had few opportunities to succeed.

• Mary notes: "A lot of times educators do not hold high enough expectations for certain groups of people--minorities, disabled, 'underachievers,' juvenile delinquents. I think it is really important to hold a high level of expectations for all students, and particularly for the disabled."

Feelings of Being Treated Differently Than Non-Disabled Children

• Treat disabled children and adults as you do others. Especially foster independent development among all children. It is especially important to nourish self-reliance in girls since many of the societal messages (e.g., media, family, church) reflect the more dependent, passive roles as being the acceptable, preferred behavior for females.

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*by Douglas Biklen and Robert Bogdan in Interracial Books for Children Bulletin, Volume 8, Numbers 6 & 7, 1977, pp. 4-9.

SUMMARY AND SUGGESTIONS FOR EDUCATORS AND PARENTS

"Don't think that disabled people can't do anything. Don't try to hold us back. Most educators believe because we're disabled we can't think. My message is: Don't believe that." Debbie

There are many obvious strains and stresses associated with teaching/counseling/parenting any individual who presents concerns outside our previous experience (and "comfort level") and/or outside the conventional definitions of "normal." Many non-disabled persons have had little or no experience in relating to disabled children or adults and consequently may have:

1) Fears about their own inadequacies;

2) Doubts about their own capacity to relate to disabled persons;

3) Concerns about the physical safety of the disabled person; and

4) Questions about the disabled person's normal bodily functions, and mental, emotional, and physical capabilities.

Furthermore, disabled individuals may share similar concerns. A woman who is spinal cord-injured in adulthood, and retains all previous abilities except the use of her legs, does not automatically have an understanding of the problems and concerns of a woman blind from birth. In this case the sensitization process especially to the problems of disabled children is similar for non-disabled women and women disabled in adulthood. It obviously cannot be assumed that because a person is disabled she or he feels immediately comfortable and capable interacting with other disabled persons.

While there may be certain concerns shared by disabled people (perhaps being viewed as "different," feeling restricted or limited unnecessarily by others), the differences among disabilities and consequent life experiences must be considered. Each human being (regardless of racial/ethnic group, sex, disability, physical appearance, personal characteristics and talents, economic level, etc.) must be viewed as unique and worthy of respect and dignity. Each person has the fundamental right to equality of opportunity, self-direction, self-determination, and free choice based on her or his individual interests, abilities, and desires.

Summary of Points

Several important issues have been raised by the collection of each woman's clear remembrance of her early school, high school, college and work experiences. Perhaps it is possible to learn from these sometimes painful, sometimes positive memories by suggesting ways for teachers, parents, and others to deal with particular problems. Each recommendation should be considered in relationship to individual children or adults and each particular disability. Suggestions should be adapted to meet the requirements and needs of specific circumstances and persons.

The following statements are an attempt to synthesize the thoughts and feelings of the women interviewed for this publication. It should not be assumed that all disabled children and/or adults necessarily share these reactions.

This section was prepared by Rita M. Costick, WEECN Editor.

- Develop similar standards for disabled and non-disabled students.

- Nicci advises: "Don't ever say the word SPECIAL! Always remember that disabled kids have the same needs as everybody else..."

Feelings That No Distinction Was Made Among the Different Disabilities

- Gain factual knowledge about diverse disabilities and the range of variability within each one. While the term "disability" implies some form of physical, mental, or emotional limitation, it does not, of course, automatically imply restrictions in all areas. For example, recently a disabled women friend reported being consistently shouted at by a new co-worker, although she had normal hearing. Because my friend is blind, the person somehow assumed she also has impaired hearing. It is obviously important that each person be treated uniquely and assessed on the basis of her or his own individual characteristics.

- Ann emphasizes: "Our disability needs to be reckoned with for what it is. On the other hand, we need to reckon with ourselves first as human beings and once we have done that, everything else will fall into place."

Feelings of Isolation, Being Separated From Others, and Being Excluded from Participation in School Activities

- Involve disabled children and adults in school and family outings, games, sports, and other activities. Do not automatically assume they can't participate because of their disabilities. Avoid the excuse "they're not interested." Give everyone a chance to learn what her or his interests are -- this takes some exploring to find out.

- Be sensitive to the potential to isolate disabled people away from a non-disabled grouping.

- Discover ways to help disabled girls and women get involved and learn how they can contribute and feel a real sense of belonging. Open up the channels to give to, and to share with, others.

- Joanne states: "I strongly feel that mainstreaming is important for every deaf child who can successfully develop basic English skills. Deaf kids should be encouraged to attend regular schools where there are special programs that can serve their communication needs. Interpreting services should be provided at all times inside and outside of classes. That way, deaf kids would develop a fuller understanding of the world while improving their communications skills."

Lack of Information About Future Career Possibilities

- Learn the real physical and mental requirements for particular career areas and specific jobs. Avoid making assumptions about the "natural" desire of disabled individuals to work with other disabled people. Allow disabled women the same free choice in career planning as others are provided.

- Identify disabled persons in the community who are employed. Visit them on the job (with disabled and non-disabled students) to gain first-hand knowledge of necessary qualifications, working conditions, and job satisfaction. Have them visit the classroom or other meeting places to share their experiences.

- Avoid providing only limited employment options for disabled people, e.g., rehabilitation counselor, teacher of the deaf. Especially consider role models and suggestions presented to disabled females--and avoid pushing any specific career goals because of apparent

abilities or what seems "appropriate" or probable under the circumstances. Every individual deserves the same chance to make her or his life career choices--regardless of disability--based on personal ability, interest, and motivation.

- Organize teachers, school administrators, parents, counselors, and others to become resources for career education and eventual career placement. Join forces with community agencies, federal and state organizations, and neighboring groups to learn about and to create possible jobs and careers for all disabled people.

Realization of the Inability Of Adults to Talk About Their Own Feelings About Disability

- Develop a support network of non-disabled adults (e.g., teachers, counselors, parents, program directors) who are interested in discussing their feelings about disability and about relating to disabled individuals. With sensitivity and mutual respect, much learning and understanding can be accomplished by candid sharing of feelings.

- Alice recommends: "Awareness programs of sensitivity training programs should be mandatory for all non-disabled educators who work with the disabled. They should learn about disabled people's feelings about disability. If they have a strong negative feeling toward working with a disabled person, they should examine that feeling. Teachers and other people in the educational system have never given themselves any space to confront their own feelings, prejudices, and opinions about disability. I think it stems from a common fear that everyone has the potential to become disabled. They avoid the subject because it's scary. They think: 'What if tomorrow I were to become like them?' Not an unrealistic feeling."

Lack of Sufficient Opportunity To Talk About Disability With Peers and with Adults

- Provide opportunity for disabled (and/or non-disabled) women to form peer groups to talk about their feelings and concerns. Make a knowledgeable person available to the group if there are questions, ideas, problems, etc.

- Discuss issues related to disability openly with an entire class, group, family, etc. Children (as well as adults) need factual information and training to deal with disability sensitively. Verbal cruelty, name-calling, and other forms of interpersonal abuse are common among children. Educators and parents alike must teach young people to respect the basic dignity and rights of others -- regardless of personal appearance or physical or mental ability. The rights of the disabled are no less critical than the rights of those who happen to be unattractive (by our society's standards), overweight, uncoordinated, or in the "slow" reading group. And yet, persons with any of these characteristics have been labeled, ridiculed, and cast aside by children in classrooms for generations. There are few among us who have not (at one point or another in our lives) fallen into an "undesirable" social catergory, and yet the painful stereotypes march on. If we are to create an honest sense of humanity in the educational system and in our homes, we cannot allow such categorization and deprecation to survive.

Steps that are taken to actively assimilate disabled children and adults into the educational mainstream will help non-disabled people as well. Such measures, carefully and thoughtfully enacted, will most assuredly expand the opportunities and alternatives for all students. It takes courage and perserverance to get what you want from life -- for women and for men, for all racial/ethnic groups; and for persons with all types of disabilities it takes special courage.

We can learn from one another. All of us can grow, expand our options, and consequently enlarge the possibilities for a happy, satisfying, productive life firmly rooted in our own self-understanding and in our willingness to help, and be helped by, other human beings. The disabled women who have shared their personal experiences with us in this publication have demonstrated courage and perserverance to pursue their own goals although often confronted with disappointments and difficulties. Their candid reflection of past occurrences and present thoughts on the educational system of which they have been a part may serve to assist everyone concerned with the full development of disabled persons.

--Rita M. Costick

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"I was not looking for my dreams to interpret my life, but rather for my life to interpret my dreams."

--Susan Sontag
The Benefactor, 1963

A Final Note...

Just as non-disabled women are now re-examining the educational experiences, career developments, and lifestyles that have been traditionally limited by sex role stereotyping, so, too have disabled women begun this self-reflection. However, because of attitudinal and cultural barriers toward disabled women, this self-examination has been a slow process.

One of the most exciting aspects of this publication is the presentation here of strong and positive role models for disabled women. The six women featured have shown us that a good and independent life for disabled women is neither unrealistic nor impossible.

The visible movement of minority groups in the last 15 years in the United States has provided disabled people with the groundwork and encouragement to assert themselves and their rights. The movement of disabled people is fighting hard to create, for themselves, powerful and positive new identities. Not surprisingly disabled women are in the forefront of this push for independence.

Educators have a unique opportunity to actively affect and improve the quality and scope of career and life options for disabled women. Several suggestions have been offered here to highlight the concerns that many disabled women share. We hope that disabled women, educators, parents, and others concerned with the growth of disabled women into full participants in society will listen closely to their words.

--CeCe Weeks and J.Corbett O'Toole

WHAT HAPPENS AFTER SCHOOL?
A STUDY OF DISABLED WOMEN AND EDUCATION

RESOURCE LIST

IDENTIFIED RESOURCE GROUPS

Mention of organizations, agencies, or projects in this publication does not imply endorsement by the Far West Laboratory for Educational Research and Development or by the United States Department of Health, Education, and Welfare/Office of Education, Women's Program Staff.

The groups identified here represent some of the available resources concerned with education and disabled individuals. The references are for descriptive information only and do not imply specific recommendation. The quality of publications and services provided by the groups listed has not been evaluated.

This list is not comprehensive. The Women's Educational Equity Communications Network encourages readers to tell us about additional resource groups.

RESOURCE GROUPS

NATIONAL DIRECTORIES

DIRECTORY OF AGENCIES SERVING THE VISUALLY HANDICAPPED IN THE US. Revised and published every two years by the American Foundation for the Blind, 15 West 16th Street, New York, NY 10011.

DIRECTORY OF ORGANIZATIONS INTERESTED IN THE HANDICAPPED. Available from: Committee for the Handicapped, People to People Program, Suite 610, LaSalle Bldg., Connecticut Ave. and L St., Washington, DC 20036.

THE ENCYCLOPEDIA OF ASSOCIATIONS. 1975. Available in libraries or from: Gale Research, Co., Book Tower, Detroit, MI 48226.

NATIONAL ORGANIZATIONS, CENTERS, AGENCIES, PROJECTS

AMERICAN COALITION OF CITIZENS WITH DISABILITIES. 1346 Connecticut Ave., NW, Washington, DC 20036. Publishes monthly newsletter, The Coalition. Annual fee for individual membership is $5.00.

BUREAU OF EDUCATION FOR THE HANDICAPPED (BEH). US Office of Education, 400 Maryland Ave., SW, Washington, DC 20202. Provides funds to states to assist in educational programs for elementary and secondary school children; supports teacher training programs, various types of research projects; supports the production of captioned films for deal persons, and the development of many educatioanl devices used by disabled persons.

BUREAU OF DISABILITY INSURANCE. Social Security Administration, Rm. 760, Baltimore, MD 21235, 301/594-2730. A program to replace part of the income lost because of a physical or mental impairment severe enough to prevent a person from working. People who get social security can also get supplemental security income, provided they are eligible for both programs.

This resource list was compiled by Rita M. Costick, Editor, Women's Educational Equity Communications Network (WEECN), Far West Laboratory for Educational Research and Development, 1855 Folsom Street, San Francisco, CA 94103, 415/565-3032 or 3000. 1978.

BUREAU OF SUPPLEMENTAL SECURITY INCOME. 108 West High-Rise, Social Security Administration, Baltimore, MD 21235. The Supplemental Security Income Program is a system of payments to the aged, blind, and disabled persons whose income falls below federally prescribed minimums, or who are eligible for state income payments with unrestricted use; amount varies from state to state.

CENTER FOR HUMAN POLICY. Human Policy Press, P.O. Box 127, Syracuse, NY 13210. Has slide shows on handicapism and integrating disabled children, children's books (fiction and nonfiction) about disabled children, handbooks for parents and teachers, and a selection of posters about disability.

CENTER FOR INDEPENDENT LIVING. 2539 Telegraph Ave., Berkeley, CA 94704, 415/841-4776. A non-profit organization run for and primarily by disabled people. Publishes The Independent, a quarterly magazine by and about people with disabilities and an information and picture resource for teachers and librarians. Subscription is included in membership fee. Write to address given for information.

CLOSER LOOK INFORMATION CENTER. Serves parents and professionals concerned about any and all disabilities. Indicate age of person, severity of condition, and kind of problem being dealt with when inquiring. Five Parent Information Centers, run by parents, operate in South Bend, IN; Concord, NH; Boston, MA: Chicago, IL; and Cincinnati, OH. For details, write: Closer Look, Suite 607E, 1201 16th St., NW, Washington, DC 20036, 202/833-4160.

COUNCIL FOR EXCEPTIONAL CHILDREN. 1920 Association Dr., Reston, VA 22091, 703/620-3660.

THE CLEARINGHOUSE ON THE HANDICAPPED. Office for Handicapped Individuals, Rm. 338d, South Portal Bldg., Washington, DC 20201.

DISABLED IN ACTION OF METROPOLITAN NEW YORK. 175 Willoughby St., Apt. 11-H, Brooklyn, NY 11201.

FEDERATION OF CHILDREN WITH SPECIAL NEEDS. 120 Boylston St., Rm. 338, Boston, MA 02116.

IRUC: INFORMATION AND RESEARCH UTILIZATION CENTER FOR PHYSICAL EDUCATION AND RECREATION FOR THE HANDICAPPED. 1201 16th St., NW, Washington, DC 20036, 202/833-5547.

NATIONAL CENTER FOR LAW AND THE HANDICAPPED. 1235 North Eddy St., South Bend, IN 46617.

THE NATIONAL COMMITTEE/ARTS FOR THE HANDICAPPED. Suite 801, 1701 K St., NW, Washington, DC 20006, 202/223-8007.

NATIONAL WHEELCHAIR ATHLETIC ASSOCIATION. 40-24 62nd St., Woodside, NY 11377.

OFFICE FOR HANDICAPPED INDIVIDUALS (OHI). Department of Health, Education, and Welfare, 330 Independence Ave., SW, Washington, DC 20201. OHI provides leadership in the development of programs and information needs, evaluates program coverages and service gaps, operates a central information clearinghouse.

THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED (PCEH). Vanguard Bldg., Rm. 600, 1111-20th St., NW, Washington, DC 20036. Encourages the employment of all handicapped persons in both private industry and government jobs.

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REHABILITATION SERVICES ADMINISTRATION (RSA). Office of Human Development, Department of Health, Education, and Welfare, Washington, DC 20201. In conjunction with state rehabilitation agencies, RSA develops and assists in the administration of rehabilitation programs which provide services for disabled persons leading to gainful employment.

SEX AND DISABILITY PROJECT, University of California. Susan Knight, Director. 814 Mission St., San Francisco, CA 94103, 415/666-1066. HUMAN SEXUALITY PROGRAM, University of California. Dr. Evalyn Gendel, Director. 350 Parnassus Ave., Suite 700, San Francisco, CA 94117, 415/666-4787.

TYPEWRITERS FOR THE DEAF, INC. P.O. Box 622, Indianapolis, IN 46206. A non-profit organization that disseminates information about the cost, purchase, and use of teletypewriters by deaf persons. Produces International Telephone Directory of the Deaf, listing schools, colleges, publications, clubs, and associations that have TTY terminals. Publishes quarterly newsletter.

RESOURCE GUIDES

ACCESS AMTRAK: A GUIDE TO AMTRAK SERVICES FOR ELDERLY AND HANDICAPPED TRAVELERS. August 1977. Available from: National Railroad Passenger Corporation, 955 L'Enfant Plaza, SW, Washington, DC 20024. For futher information, call Amtrak's toll-free number located in the telephone directory for information and reservations. Nationwide teletypewriter (TTY) toll-free number is 800/523-6590 or 91; in Pennsylvania, call 800/562-6960.

ACCESS--THE GUIDE TO A BETTER LIFE FOR DISABLED AMERICANS. Lilly Bruck. 1978, 251 p. Available from: Random House, Inc., 201 East 50th St., New York, NY 10022, $5.95.

ACCESS NATIONAL PARKS, A GUIDE FOR HANDICAPPED VISITORS. A.N. Wilson. 1978. 200 p. Available from: Government Printing Office (GPO) Bookstore, Majestic Bldg., 720 North Main St., Pueblo, CO 81003, 303/544-3142 or FTS 323-9371, or from Superintendent of Documents, US GPO, Washington, DC 20402; stock number 024-005-00691-5, $3.50.

ACCESSIBILITY OF JUNIOR COLLEGES FOR HANDICAPPED. Available from: Education Committee, The President's Committee on Employment of the Handicapped, Vanguard Building, Rm. 600, 111-20th St., NW, Washington, DC 20036, free.

ARTS AND THE HANDICAPPED: AN ISSUE OF ACCESS. Presents brief descriptions on traveling art shows for the blind, the arts in community service centers, the arts in colleges, and other programs and activities. Available from: Educational Facilities Laboratories, 850 Third Ave., New York, NY 10022, $4.00.

AIR TRANSPORTATION OF HANDICAPPED PERSONS. Advisory Circular No. 120-32. Available from: Federal Aviation Administration, Department of Transportation, Distribution Unit, Washington, DC 20590.

BARRIER FREE DESIGN: A SELECTED BIBLIOGRAPHY. Annotated resources for the disabled, elderly, planners, architects, and others interested in the design of the environment. Available from: Paralyzed Veterans of America, Inc., 7315 Wisconsin Ave., Suite 300W, Washington, DC 20014.

CAREERS FOR THE HOMEBOUND--HOME STUDY EDUCATIONAL OPPORTUNITIES. Available from: President's Committee on Employment of the Handicapped, Washington, DC 20210.

THE COLLEGE GUIDE FOR STUDENTS WITH DISABILITIES. Elinor Gollay and Alwina Bennett. 1977 and 1976, 545 p. Available from: Abt Associates, Inc., Publications Division, 55 Wheeler St., Cambridge, MA 02138; 1977 edition $30.00, 1976 edition, $18.50, $12.00 to the disabled.

DIRECTORY OF NATIONAL INFORMATION SOURCES ON HANDICAPPING CONDITIONS AND RELATED SERVICES. 1976, 405 p. US Department of Health, Education, and Welfare. Available from: US Government Printing Office, Washington, DC 20402, $6.50.

DIRECTORY OF PROGRAMS AND SERVICES. AMERICAN ANNALS OF THE DEAF. American Annals of the Deaf is a journal published 6 times a year (for $12.50). Each year the April issue consists of a fully-revised directory. Available from: American Annals of the Deaf, 5034 Wisconsin Ave., NW, Washington, DC 20016, $5.00.

GETTING THROUGH COLLEGE WITH A DISABILITY. Available from: President's Committee on the Employment of the Handicapped, Washington, DC 20210, free.

A GUIDE TO COLLEGE/CAREER PROGRAMS FOR DEAF STUDENTS. 1975. Available from: The Office of Demographic Studies, Gallaudet College, Kendall Green, Washington, DC 20002, free.

HANDBOOK FOR BLIND COLLEGE STUDENTS. Available from: National Federation of the Blind, Student Division, 3800 West Michigan St., Apt. 701, Indianapolis, IN 46222.

HELPING HAND SERVICE FOR THE HANDICAPPED. Available from: Greyhound Lines, Greyhound Tower, Phoenix, AZ 85077.

LIBRARY RESOURCES FOR THE BLIND & PHYSICALLY DISABLED. 1977. A Directory of DBPH Network Libraries and Machine Lending Agencies. Available from: Library of Congress, Division of the Blind and Physically Handicapped, Washington, DC 20542.

A LIST OF GUIDEBOOKS FOR HANDICAPPED TRAVELERS. Lists accessibility guidebooks available in a number of American cities, with the titles and distributors of the local guidebooks. Available from: The Women's Committee, the President's Committee on Employment of the Handicapped, Vanguard Bldg., Rm. 600, 1111-20th St., NW, Washington, DC 20036, free.

PARATRANSIT. AN ALL NEW VEHICLE FOR PUBLIC TRANSPORTATION. UMTA Office of Public Affairs, US Department of Transportation, Washington, DC 20590.

REGISTRY OF INTERPRETERS FOR THE DEAF. Available from: P.O. Box 1339, Washington, DC 20013.

TRANSBUS...WHAT IT CAN DO FOR YOU. Available from: The Transbus Group, 1315 Walnut St., 16th Floor, Philadelphia, PA 19107.

VOCATIONAL AND EDUCATIONAL OPPORTUNITIES FOR THE DISABLED. 1977. Available from: Insurance Company of North America and Human Resources Center, I.U. Willets Rd., Albertson, NY 11507.

THE WHEELCHAIR TRAVELER. Identifies room prices, dining facilities, transportation services, and other amenities. Available from: The Wheelchair Traveler, Ball Hill Rd., Milford, NH 03055.

PERIODICALS

ACCENT ON LIVING. Available from: P.O. Box 700, Gillum Rd. and High Dr., Bloomington, IL 61701.

AMERICAN FOUNDATION FOR THE BLIND RESEARCH BULLETIN. Available from: American Foundation for the Blind, 15 West 16th St., New York, NY 10011; semi-annually, single issues $2.50, four-issue subscription $9.00.

AMERICAN REHABILITATION. Available from: Superintendent of Documents, GPO Box 1533, Washington, DC 20402; bimonthly, $11.75 a year.

AMICUS. Reports on legislation and court decisions. Available from: The National Center for Law and the Handicapped, 1235 North Eddy St., South Bend, IN 46617; bimonthly, free.

THE BRAILLE FORUM. Published by the American Council of the Blind, Oklahoma City, OK. Available in braille, large-type, flexible disc (8 1/3 rpm), and cassette tape from: The Braille Forum, 190 Lattimore Rd., Rochester, NY 14620; monthly, free.

COPH BULLETIN. Available from: National Congress of Organizations of the Physically Handicapped, 7611 Oakland Ave., Minneapolis, MN 55423; quarterly, $1.50 per year or $0.50 per copy.

CLOSER LOOK REPORT. Distributes free information packets. A project of the Office of Education, HEW, Bureau of Education for the Handicapped. Available from: The National Information Center for the Handicapped, Box 1492, Washington, DC 20013.

THE EXCEPTIONAL PARENT. Articles and guidance for parents of disabled children. Available from: P.O. Box 4944, Manchester, NH 03108; six issues per year, $10.00 individual, $12.00 institutional.

THE INDEPENDENT. "A New Voice for the Disabled and Blind." Available from: Center for Independent Living, 2539 Telegraph Ave., Berkeley, CA 94704; quarterly.

MADNESS NETWORK NEWS. "A Journal of the Anti-psychiatry/Psychiatric Inmates' Movement." Available from: P.O. Box 684, San Francisco, CA 94101; six issues per year, $4.00 individuals, $6.00 institutions, $0.50 per copy.

PARAPLEGIA NEWS. Published by the Paralyzed Victims of America. Available from: 935 Coastline Dr., Seal Beach, CA 90740; monthly, $4.00.

PERFORMANCE. Available from: The President's Committee on Employment of the Handicapped, 1111-20th St., NW, Washington, DC 20036; monthly, free.

PROGRAMS FOR THE HANDICAPPED. Available from: Office of Handicapped Individuals, Office of the Assistant Secretary for Human Development, Department of Health, Education, and Welfare, Washington, DC 20201; monthly, free.

RECORD. The official publication of the Social and Rehabilitation Service, HEW. The Record serves as a means of improving the management of human service programs--assistance payments, individual and family social services, medical services, and vocational rehabilitation. As a management tool the magazine is intended to aid professional personnel in state and local agencies, public and private, to carry out their responsibilities more effectively. Available from: Superintendent of Documents, Government Printing Office, Box 1533, Washington, DC 20402; 10 times per year, $6.40.

REHABILITATION GAZETTE. See article in Volume XX, 1977, "A Compendium of Employment Experiences of 25 Disabled Women." Available from: 4502 Maryland Ave., St. Louis, MO 63108; yearly, donation of $3.00 from disabled persons, $6.00 from non-disabled.

SPORTS 'N SPOKES, THE MAGAZINE FOR WHEELCHAIR SPORTS AND RECREATION. Available from: 6043 North Ninth Ave., Phoenix, AZ 85013; bimonthly, $4.00 per year.

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TRENDS. Includes articles on topics such as making recreational areas accessible, disabled persons' needs in recreation areas, and listings of public and private groups who offer additional information and resources on related subjects. Available from: The Park Practice Program, National Recreation and Park Association, 1601 North Kent St., Arlington, VA 22209; quarterly, $10.00 initially, $8.00 on renewal.

ARTICLES AND BOOKS

CAREER EXPLORATION AND PREPARATION FOR THE SPECIAL NEEDS LEARNER. L. Allen Phelps and Ronald J. Lutz. Includes detailed suggestions for creating workable programs. Available from: Allyn and Bacon, Inc., Rockleigh, NJ 07647, $15.95.

"Education of Handicapped Children." FEDERAL REGISTER, August 23, 1977, Vol. 42, No. 163, Part II, p. 42474-42518. Reprints are available from: US Government Printing Office, Washington, DC 20402, $0.75.

FEMALE SEXUALITY FOLLOWING SPINAL CORD INJURY. Elle Fridman Backer. 1978, 273 p. Available from: Accent Special Publications, Cheeves Publishing, Inc., P.O. Box 700, Bloomington, IL 61701, $10.95.

HANDICAPPING AMERICA. Frank Bowe. 1978. Availabe from: Harper and Row Publishers, Inc., 10 East 53rd Street, New York, NY 10022, $10.00.

"Handicappism." 1977. Special double issue of INTERRACIAL NEWS FOR CHILDREN BULLETIN, Vol. 8, Nos. 6 & 7. Available from: 1841 Broadway, New York, NY 10023.

THE HIDDEN MINORITIES: SEX AND RACE ARE NOT ENOUGH. Joan F. Jaffe. 1977, 24 p. Available from: Educational Resources Information Center (ERIC), Document Reproduction Service, Box 190, Arlington, VA 22210, order number ED 149 379, microfiche $0.83; paper copy $1.67. Discusses society's hidden minorities: the handicapped, the aging, those with different lifestyles. Critiques children's books about disabled children and adults; three-page bibliography.

"The Influence of Sexism on the Education of Handicapped Children." 1974. Reprinted article available from: Project on Equal Education Rights (PEER), 1029 Vermont Ave., NW, Suite 800, Washington, DC 20005, free.

JOBS FOR THE DISABLED. Sar A. Levitan and Robert Taggart. 1977. Available from: John Hopkins Press, Baltimore, MD 21218. $3.50.

MAINSTREAMING. Forthcoming nonsexist, multiracial materials which show disabled children and adults interacting with the non-disabled in a variety of school, work, and play scenes. For further information, contact: The Nonsexist Child Development Project, The Women's Action Alliance, Inc., 370 Lexington Ave., New York, NY 10017, 212/532-8374.

"Nondiscrimination on Basis of Handicap." FEDERAL REGISTER, May 4, 1978, Vol. 42, No. 86, Part IV, p. 22676-22702. Reprints are available from: US Government Printing Office, Washington, DC 20402, $0.75.

PERSPECTIVES IN EDUCATION OF THE DEAF. Proceedings of National Forum V. Council of Organizations Serving the Deaf. Available from: US Government Printing Office, Washington, DC 20402, $0.95.

TOWARD INTIMACY: FAMILY PLANNING AND SEXUALITY CONCERNS OF PHYSICALLY DISABLED WOMEN. The Task Force on Concerns of Physically Disabled Women. 1978, 63 p. Available from: Human Sciences Press, 72 Fifth Ave., New York NY 10011, $2.50.

THE UNFINISHED REVOLUTION: EDUCATION FOR THE HANDICAPPED. 1976 Annual Report. National Advisory Committee on the Handicapped, US Department of Health, Education, and Welfare, Washington, DC 20201.

WITHIN REACH: PROVIDING FAMILY PLANNING SERVICES TO PHYSICALLY DISABLED WOMEN. The Task Force on Concerns of Physically Disabled Women. 2nd Edition, 1978, 48 p. Available from: Human Sciences Press, 72 Fifth Ave., New York, NY 10011, $2.95.

NONPRINT MEDIA

FEELING FREE. Tapes and films on disabled young people with accompanying print materials. Tapes and films available from: Scholastic Magazine, 50 West 44th St., New York, NY 10036, 212/ 867-7700. Print materials available from: Human Policy Press, 216 Ostrom Ave., Syracuse, NY 13210.

KEVIN. Kevin is blind. This film sharpens our awareness and appreciation of sight. Available from: Churchill Films, 662 West Robertson Ave., Los Angeles, CA 90069.

LIKE OTHER PEOPLE. A love story featuring an English couple with cerebral palsy. It is a film dealing with sexual, emotional, and social needs. Available from: Perennial Education, Inc., 1825 Willow Rd., Northfield, IL 60093.

MIMI. In this film, we see the world through the eyes of a young woman who is permanently disabled. Available from: billy bud films, Inc., 235 East 57th St., New York, NY 10022.

REALITIES OF THE PHYSICALLY HANDICAPPED. Helen Jones and Dick Farr. Audio-cassette program with 6 cassettes and 12 presentations. Topics include accepting a disability, architectural barriers and housing, transportation, recreation, sexuality, marriage, and parenthood. Available from: Affective House, PO Box 35321, Tulsa, OK 74135, $69.50.

APPENDIX

"THE NEW EDUCATION LAW: WHAT DOES IT MEAN?"

"YOU HAVE NEW RIGHTS—USE THEM!"

"GUIDELINES FOR THE REPRESENTATION OF EXCEPTIONAL PERSONS IN EDUCATIONAL MATERIALS"

These articles are reprinted from . . .

REPORT FROM

CLOSER LOOK

A Project of the U.S. Department of Health, Education, and Welfare
Office of Education, Bureau of Education for the Handicapped

The New Education Law: What Does It Mean?

The Education for All Handicapped Children Act of 1975 (Public Law 94-142) is based on the right of *all* American youngsters, with no exceptions, to an education. The law's detailed blueprint was written to correct old and widespread injustices. Its primary goal is to give every child, including the most severely handicapped, the learning opportunities he needs to become as self-sufficient and productive as possible.

According to current estimates, approximately half the nation's 8 million handicapped children are now denied the kind of education they should have in order to reach their potential. As many as 1 million children are totally excluded from school. This new legislation goes further than any other law in our history to try to reach these children and change the direction of their lives. In the exact words of the law, its aim is:

> "to assure that all handicapped children have available to them . . . a free and appropriate education which emphasizes special education and related services designed to meet their unique needs."

The federal government will help to pay for added costs

Under the law, states will be eligible to participate in an ongoing program of federal aid to pay part of the additional cost of educating handicapped children. In order to qualify for federal assistance, each state is required to submit a plan to the federal government showing how it will carry out its commitment to the goal of free and appropriate education for all handicapped children. The ages to be served are 3 to 18 by September 1978 and 3 to 21 by September 1980.

The law makes it possible for *local* school systems, too, to receive a share of federal funds, as long as the requirements specified by law are met. Local school districts must prepare detailed plans for state approval, showing how they will fulfill the purposes of the law.

What are the key provisions of the law?

It is of great importance to all parents of handicapped children to know what the law says. Here are some of its key provisions:

- Highest priority must be given, first, to handicapped children who are not now receiving an education, and, second, to the most severely handicapped children whose education is inadequate.
- Strong safeguards of the due process rights of parents and children must be guaranteed by states and localities. These safeguards protect parents' rights in all procedures related to the identification, evaluation and placement of their children, and the provision of an appropriate education for their children. They also provide for the opportunity to protest educational decisions made by school officials.
- The law gives strong impetus to educating children in the "least restrictive environment." It requires that children be placed in special or separate classes only when it is impossible to work out a satisfactory placement in a regular class, with supplementary aids and services. This will be one of the basic considerations in designing appropriate programs for each child.
- All methods used for testing and evaluation must be racially and culturally non-discriminatory, and must be in the primary language or "mode of communication" of the child. No one test or procedure may be the sole means of making a decision about an educational program.
- Individualized education plans are to be prepared for each child, with parents participating on the team that draws up the plan. (The child, too, is to be included, when appropriate.) These prescriptions must include short and long term educational goals and specific services to be provided. This provision is to go into effect in the school year beginning in 1977, and says that all individual plans must be reviewed at least annually and revised according to the child's changing needs.
- When children are placed in private schools by state or local education systems in order to receive an appropriate education, this must be done at no cost to parents; private school programs must meet standards set by law and

(continued on page 2)

schools must safeguard the rights of parents and children guaranteed by law.

- The law encourages the development of programs for preschool children by creating a special incentive grant to states for providing services to handicapped children aged 3 to 5. (Grants can be up to $300 for each child served.)
- Each state must set up an advisory board, including handicapped individuals, teachers, and parents of handicapped children. This board is to advise the state on unmet needs, comment publicly on rules and regulations and assist in evaluating programs.
- Funds can be withheld if, after reasonable notice and an opportunity for a hearing, a state is found by the U.S. Commissioner of Education to have failed to comply with the Act.
- Payments by the state to local school systems may also be suspended for non-compliance. If the state determines that a locality is unable or unwilling to set up or consolidate programs, or has children who can best be served by regional or statewide programs, the state will use the funds to provide services directly to those children.

The men and women in state and local education offices who are working hard to translate the letter of the law into reality need your input, your ideas and your knowledge about *real* needs of *real* children — your own. The law opens the door to a great deal of participation by parents. Both state and local education departments are required to provide opportunities for comment by the public before their plans or policies are adopted. By contacting your state or local director of special education, you can find out when hearings will be held, ask to see copies of plans that are drawn up, and arrange to make your views known. You can discuss your concerns with the parent members of the Advisory Board, too — as a way of being heard.

FIND OUT HOW "SECTION 504" CAN HELP YOU!

Another historic piece of legislation is opening up equal opportunities for handicapped children. It is Section 504 of the Rehabilitation Act of 1973, and it protects not only the right to education, but the right of all handicapped people to participate fully in community life.

Section 504, in simple, clear language, prohibits discrimination against handicapped persons by any agencies or organizations which are assisted by federal funds. Recently, the U.S. Department of Health, Education and Welfare issued regulations which spell out in detail how it will carry out Section 504.

These federal regulations require that all public and private groups which receive HEW funds must take specific steps to make it possible for people with mental, physical or emotional handicaps . . . "to learn, work and compete on a fair and equal basis." The penalty for discrimination can be loss of federal funds.

This is an extremely strong commitment by the federal government to promote the rights of handicapped citizens. The regulations call for:

- Free, appropriate education for all handicapped children, regardless of the nature or severity of the handicap
- Positive efforts to create job opportunities so that a disability is no longer a barrier to employment
- College and post-secondary vocational education which is adapted to needs of handicapped students
- Equal treatment of handicapped persons by health, welfare and social service agencies

The key word in the entire set of regulations is *access*. All HEW-assisted facilities *must* be barrier-free. The regulations state that if special adaptations won't work (such as assigning classrooms to accessible locations), structural changes must be made within the next 3 years. *No exceptions to program accessibility will be allowed.*

But access means more than that. The regulations are filled with examples of special aids and adaptations that must be provided so that services are really available to handicapped individuals. Among the requirements are: interpreters for deaf persons, taped tests, brailled materials and readers for students with visual handicaps, specially adapted equipment for manual impairments, academic curriculum modifications by post-secondary programs.

The regulations also stress the importance of designing educational programs to meet individual needs, and have set down other policies that coordinate with *The Education for All Handicapped Children Act*. This clearly adds great force to the implementation of educational rights.

As they now stand, 504 regulations apply to states, counties, cities, public and private schools, colleges, universities, hospitals, clinics and numerous other "recipients" of HEW funds which provide programs and services. Regulations similar to those written by HEW will be issued to cover agencies which receive funds from other federal departments.

This is just a brief sketch of Section 504 regulations. Get a complete copy, and study it carefully. Parents of handicapped children and youth — and all handicapped citizens — should know what these regulations say. Write to: U.S. Department of Health, Education and Welfare. Office for Civil Rights, Washington, D.C. 20201. And — if you want to file a complaint about discrimination, write to the same address to find out what steps to take.

Know Your Rights! . . . A Special Issue

REPORT FROM

CLOSER LOOK

A Project of the Parents' Campaign for Handicapped Children and Youth

FALL 1977

You Have New Rights — Use Them!

At the beginning of this school year, some extremely important things happened which have strengthened the rights of handicapped children—and their parents.

- Final federal regulations were issued, spelling out clearly how The Education for All Handicapped Children Act (Public Law 94-142) will actually work. The regulations were published in August and went into effect October 1. They reinforce our national commitment to a free, appropriate education for every handicapped child, including the most severely disabled. And they set up detailed procedures for achieving that goal.
- Earlier in the year, in April, the federal government took action to enforce the rights of all handicapped people by setting down strong regulations for Section 504 of the Rehabilitation Act of 1973. These regulations assure equal opportunities for the handicapped in every facet of community life; in the area of education, they make clear that no handicapped child may be excluded from publicly supported schooling; that schools (including post-secondary and vocational schools) must be accessible to all; that education must meet individual needs. If a school system persists in denying the rights of the handicapped, it faces the possibility of loss of federal funding. (Section 504 prohibits discrimination against handicapped individuals of all ages by any agency or organization receiving federal funds.)

Both of these government actions have a direct impact on the lives of handicapped people—an impact which is only beginning to be felt. Both laws, strong and far-reaching as originally written, now have the additional force of specific rules for implementation. There are, some advocates point out, certain ways in which these regulations could have been made even stronger in protecting the rights of the handicapped. But as they stand, they provide new and effective means for bringing handicapped people into the mainstream, at last.

No law is a panacea, and no law can automatically relieve parents and handicapped young people of their frustrations with systems that have only recently begun to include them. The important fact to remember is that opportunities are now available to parents that never existed before. In most cases, it's still going to take hard, persistent work—to make sure that handicapped kids get the education they need. But new opportunities are there—and parents must know how to seize them.

The recognition of the role, and the rights, of parents of handicapped children is one of the most significant changes in public policy brought about by Public Law 94-142. There is no longer any legitimate debate about whether parents should participate in planning and monitoring their child's educational program. Every step along the way—from the time a child's special need is first suspected—a parent's right to take action is now protected by law.

We've put this special issue of our newsletter together *not* to describe each specific regulation of P.L. 94-142, but to help parents use these new legal tools —and sharpen their own skills in fighting for equal opportunities for their children.

We receive letters from parents every day about school programs that are inadequate—or worse. The parents of a ten-year-old daughter born with Down's Syndrome write that she was in kindergarten for two years and a "baby-sitting" first grade for the next three

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You may think we've forgotten you. We haven't. You are still on our mailing list. The fact is that the high cost of printing and distribution has made it necessary for us to combine our issues—and publish only twice each year. So, please be patient. We care about communicating with you, and you'll continue to hear from us . . . just a little less often.

because the principal had said "she can't learn anything." A mother writes that she has battled unsuccessfully for thirteen years to get her child, who is diagnosed as having learning disabilities, out of a school "dumping ground." And the father of a teenaged boy writes in agony about years of failure. He asks urgently for some help in finding vocational education so that his son won't drown in his own defeat.

These parents now have the right to demand that their schools do something *at once* about such situations. Programs *must* be reviewed, must take into account each child's individual needs, and must contain specific, appropriate services. Individualized education programs (referred to as IEPs) must be drawn up for every handicapped child—and must be changed as children change.

By law, these programs must be designed by teams including the child's teacher, a school administrator and—you, the parent. *You belong at that conference table.* Your voice in decisions about what happens to your child in school is essential. Your instinct and knowledge about your child are invaluable—and besides, *you* are the one who has the prime responsibility for your child's welfare, not just today, but in the years to come.

This team approach is a new scenario for most people—both parents *and* professionals. We're all going to have to learn a great deal more about working together. There are many school professionals who welcome the idea of conferring with parents as equals, and see the benefits that flow from that relationship. There are others who do not welcome the idea at all, and give it lip service at best. Schools have always been *their* turf, and some of them tend to feel defensive about meetings with parents, as if they were under attack. Often, they see parents as overdemanding and pushy, or apathetic and uncooperative, not realizing that parents frequently are reacting to years of being shoved out of school offices. Many parents, on the other hand, feel shaky about contacts with the school, as if they didn't know enough to hold their own. Others may have become so angry and overbearing that they trigger hostile reactions without even realizing it. New habits of thinking and behaving are needed—not only to make meaningful planning possible, but also to open up lines of communication—so that problems can be dealt with as they come up.

This is a changing school scene, requiring more candor and open discussion, more willingness to face up to our own limitations, to recognize our own biases and see the value of pooling our thoughts and energies. What's wrong, for instance, with administrators admitting openly to parents that they must have more trained teachers and special equipment in order to serve handicapped children adequately—and then going together to the school board or state legislature, to speak up for more funding to create better programs?

It doesn't always work that way. Resistance to change is a reality. There are difficult problems, tragic problems that parents have had to live with for years. And although the law sets up machinery for solving problems through persuasion and understanding, meetings and discussions can break down. To take care of deadlocked situations, a system for settling disputes through impartial hearings is written into the law. This system for protest and appeal is going to require a lot of new learning, too. It can be cumbersome, draining and deeply frustrating.

Unquestionably, parents need help in learning the ropes. Training for parents—not just for teachers—could make things work a lot more smoothly for everyone. Advocacy organizations are taking on this assignment, and courses are springing up in how to get school services under new laws. It's a good idea; in fact, it should be a priority for every parent group. Some parent groups are beginning to set up programs for sensitizing school professionals, administrators and school board members, too, to the kinds of problems that families of handicapped children must cope with. Efforts like these can change old styles, air old grievances and possibly even bury them . . . so that we can get on with a new, fruitful collaboration between parents and professionals.

Parents are in the decision-making act now, where they belong. It may take some practice—but you can do it! In fact, this is really what hundreds of brave and forceful parents have been doing for years, as they've fought to get their kids out of inferior classrooms, insisted that children who were failing get special teaching, gone doggedly to meeting after meeting to convince schools to accept children who were considered "ineducable."

There's a difference now. A big difference. Now parents have the law on their side. If you and your child have been turned away from school, told "we don't take children like that" or given an exhausting run-around when you tried to get necessary services, this is the time to try again. (And please get the help of an experienced parent or other advocate if you possibly can!)

In the pages that follow, we've tried to be as specific as possible about some of the basic do's and don'ts of parent participation. We hope you'll find these useful. Don't forget . . . the rights of parents are there to protect the rights of children. Learn them . . . and use them!

DUE PROCESS

IN A NUTSHELL

Throughout this guide, we've indicated times when due process enters the picture. Here's a quick review to keep in mind the main steps involved in due process. Each of these steps reinforces your right to stay on top of decisions about your child.

1. You must receive notice in writing before the school system takes (or recommends) any action that may change your child's school program. Notice in writing is also required if a school refuses to take action to change your child's program.

2. You have the right to give—or withhold—permission for your child to be: tested to determine whether or not he requires special education services (identification); evaluated by specialists to determine what his educational needs are (evaluation); placed in a specific school program to meet his needs (placement).

3. You have the right to see and examine all school records related to the identification, evaluation and placement of your child. If you find that certain records are inaccurate or misleading, you have the right to ask that they be removed from your child's file. Once removed, they may *not* be used in planning for your child's placement.

4. If you do not agree with the school's course of action at *any* point along the way, you have the right to request an impartial due process hearing. This means that you can initiate a hearing to protest any decision related to identification, evaluation or placement of your child.

5. If you fail to win your case, you have the right to appeal the results of the due process hearing to the State Department of Education; and you can appeal to the courts if you lose your case at the state level.

Calling for a due process hearing is your right, but remember that it can be an exhausting process. Before going this route, be sure you have tried to settle differences through every other means—by being as persuasive as possible in meetings with teachers, the principal, special education administrators. If you know that you're up against a brick wall, and you're sure that a due process hearing must be held to resolve conflicting points of view, then you must prepare your case as thoroughly as possible. Be sure to get help from an advocacy group or a lawyer who is familiar with education law and procedures in your state, or an experienced parent. (According to law, the school system must tell you about sources of free or low-cost legal aid. Ask for this information.)

Know your rights at a hearing:

- The hearing officer must be impartial, may not be employed by the school district or involved in the education of your child.
- You have the right to legal counsel (which includes the advice and support of any advocate, not necessarily a lawyer); to examine witnesses; present evidence; ask questions of school spokespeople; obtain a record of the hearing and all of its findings.

NOTE: Write directly to the superintendent of schools in your district to request a hearing. Hearings must be held not later than 45 days after requested. State Departments of Education must review appeals within 30 days.

HOW CAN CLOSER LOOK HELP YOU WITH ALL OF THIS?

We realize we're giving you lots of advice and that you may need someone to help make things happen. That's what we're here for—to help you locate people in your own area who can give that extra push. So, please write to us, and we'll do our best to boost your efforts. (When you write, it will help to tell us your child's age—and handicapping condition, if he has been diagnosed.) We'll put together as much information as we can to help you out.

If you're looking for an advocate to accompany you to a school meeting on your child's Individualized Education Program (or if you want to talk with other parents who have some know-how), it will help to contact a parent group in your community. We can give you names of organizations whose members are well-informed about federal and state laws, and the steps to follow all the way from testing to due process hearings.

If you want to read more about your child's disability, we can provide lists of books written by parents who have lived through the same trials you're facing. We will also be glad to tell you about other reading you can do about rights.

If you are uncertain about the meaning of psychological and educational testing we can give you a free booklet which can help you understand the purpose and shortcomings of the more well-known tests. (This booklet might also be helpful to your child's teacher.)

In short, we're here to help you within the limits of our resources. Let's hear from you!

Planning Your Child's Education: You Belong on the Team!

Do's and Don'ts for Parents

Laws can seem terribly formidable. It's hard to feel that they really apply to one's own son or daughter. When it comes to figuring out what they mean, our tendency is to leave it all to the "experts."

But we can't. Laws belong to us. You don't have to be a lawyer to understand a law—or to use it to change your life and your child's life.

The following *Do's and Don'ts* can help you use specific parts of The Education for All Handicapped Children Act which give parents new rights. Each of those parts relates to the ultimate goal of the law: to provide free and appropriate education services for every handicapped child. Each part interconnects with the others like pieces in a puzzle. These important pieces—*testing and evaluation, individualized education programs (IEPs) and due process*—need you, the parent, to be sure they fit together . . . and work.

None of these procedures is going to work perfectly. There are bugs in every system, and loopholes. Getting appropriate services is still going to be hard work. We hope these pointers will strengthen your hand. Not every one will apply to you; find what fits your situation, and make use of it. Good luck!

IF YOUR CHILD HAS SPECIAL NEEDS, TELL THE SCHOOL ABOUT IT!

DO . . . Get in touch with your local superintendent of schools without delay if your child has a handicap and is not in school. Your school system is obligated to find all children with disabilities. According to law, no child may be excluded from school because of a handicap. Ask that your child be given an evaluation to find out what kind of program he should have.

The school must take a careful and thorough look at any child who may need special services—by providing a comprehensive evaluation. *Once a child is found eligible for special education, the school must arrange to provide appropriate services; a meeting to prepare an individualized education program must be held within 30 days.*

Don't forget: all this applies not only to young children, but also to high school age youth with physical, mental and emotional disabilities. They are too often a forgotten population!

DO . . . Find out about preschool services for handicapped children. A great many state laws now call for special programs starting at age three, at least for certain specific disabilities. The principal of your local school (or the district superintendent) can tell you more about available programs. P.L. 94-142 provides incentives for education of children with handicaps between ages 3 and 5, and programs are growing.

DO . . . Make every effort to work with your child's classroom teacher if your child is already in school, but is having problems. There may be some discoveries you and the teacher can make together—things that can be done *right now*, during school hours or after, that can help your child. It will take thought, insight, willingness to try out suggested new activities that can add up to a brighter outlook for your youngster. Some preliminary screening may be done, too, to see if more specialized help is needed at the present time. If problems persist, don't let things slide. If you suspect that your child does have a disability *do* go ahead with procedures for getting an evaluation. (Your child's teacher, counselor or principal may carry the ball on this. If not, act on your own.)

DO . . . Remember that you can ask for a re-evaluation even if your child is already placed in a special education program. This is especially important if you feel the placement was based on old, inaccurate or incomplete tests—or if you are dissatisfied with the program. Also, it is important to keep track of a child's needs to make sure that his program continues to be really appropriate, to see if he is ready for a change, or whether his program can be improved.

DO . . . Put your request for an evaluation *in writing*—to the principal of your school or the superintendent. Keep copies of the correspondence. If vital information is discussed on the phone, write a letter confirming the gist of the conversation. Don't trust important matters (like the date, time and place of an evaluation, or what professionals are in charge of testing your child) to memory.

Due Process comes in here. You must receive a written notice from your school system asking your permission to test your child (even if you have requested the evaluation). An explanation of all your rights should be included, including your right to inspect and review all relevant school records about your child.

You must also get a notice in writing if the school turns down your request for evaluation, explaining why. If you can't get an explanation that satisfies you, and you wish to protest this decison, you can request a due process hearing at this point.

DO . . . Keep your own rights file! Use it to document any steps you take to find appropriate education and related services for your child—from the "suspicion of need" stage on up. The file should include: diagnostic test results and other professional reports, your own notations of attempts by you or your child's teacher to solve problems, reports from teachers about your child, copies of letters to and from school officials. Keep copies of state and federal laws and procedures

for education of handicapped children and other relevant information. You'll need all this—to keep track of your child's progress, and to stand up for his rights if the school fails to provide an adequate program.

WHAT SHOULD YOU KNOW ABOUT TESTING AND EVALUATION?

DO . . . Be sure that the evaluation of your child is complete . . . that it does not consist only of a single test aimed at pinning an IQ score or any other label on him . . . but is a well-rounded stock-taking by a team of specialists that tells how your child is doing in all areas of his intellectual, physical and emotional development. This is the only way an *appropriate* education program can be provided. Information may be gathered in different ways . . . by talking to people who know your child (including doctors or other professionals), by conferring with classroom teachers, by meeting with you, by observing your child and giving him some tests.

DO . . . Make sure your child has a complete physical examination. This is a must. A child who is thought to be retarded may actually have a visual impairment that has never been discovered. Other difficulties may be caused by hidden physical conditions.

DO . . . Remember—calling a child handicapped by this or that condition does not tell us about his potential, how he learns best, what he *can* do.

DO . . . Talk about your own observations of your child's behavior, strengths and weaknesses to members of the evaluation team—to a guidance counselor, or social worker or school nurse. People who do the evaluating must know how a child acts and reacts with different people, in different settings, at different times . . . in school, on the playground, in his own neighborhood. Your first-hand, round-the-clock knowledge of your child is important information, and should be part of the assessment of your child's needs.

DO . . . Ask what tests will be given to your child, and why. When you sign your name giving permission to have your child tested, make your signature count. Find out what information these tests will yield that can help you and the school know how your child learns, what skills should be strengthened or developed, what problems he has to deal with, what special help he needs. Inform yourself as fully as possible about what these tests are expected to do—before giving your consent to have your child tested. (Tests may be a big mystery area for you, as they are for most people. How about making a study of testing and evaluation through your local parent group or PTA?)

DO . . . Be sure that testing does not discriminate in any way. If a child speaks Spanish, or any language other than English, tests must be given in the language he knows best. Children who have grown up in minority cultures should not be judged by answers to questions about a world that is totally strange to them. Children who are deaf must have interpreters; all testing must take the nature of handicaps into consideration, so that the picture of a child's ability is a truly fair one.

DO . . . Insist that the results of testing and evaluation be explained to you in clear, jargon-free terms, and that you have copies for your own file.

Due process comes in here. If you do not feel that the school's evaluation is fair or accurate, you are permitted by law to get an independent evaluation from other professionals. But—you may end up paying for it. The school system can ask for a due process hearing when its evaluation is challenged, to decide whether or not an outside evaluation is necessary. If the ruling is in the school's favor, the school does not have to pay. If you do get an independent evaluation (whether or not the school pays for it) it must be considered in decisions about placing your child —and it may be used as evidence in a due process hearing.

Testing will not necessarily mean that your child will be found eligible for special education. If you feel that the school's decision is wrong on this score, you can request a due process hearing at this point.

GET READY FOR MEETINGS TO DECIDE WHAT'S BEST FOR YOUR CHILD

DO . . . Be sure to attend all meetings held to plan or check into your child's individualized education program (IEP). The law states clearly that an IEP team *must* include one or both parents, the child's teacher and a representative of the school system. (Sometimes, one or more other specialists may be there, too. If this is the first time your child will get special services, someone who was involved in testing your child must be present.) Schools are expected to make every effort to get in touch with parents to make sure that they come to IEP meetings—and to arrange times that they *can* come.

IEPs must be prepared for every child who is eligible for special education. If no individualized education program has been drawn up for your child, check into it. This programming is the key to getting appropriate services.

DO . . . Prepare as well as you can for the school meeting that will design your child's educational program. Have your child's file ready, with information easily available on all testing and evaluation that has been done—by the school, or privately. Use your right to go through school records to be sure they are accurate and up-to-date. This meeting *must* be based on a recent and comprehensive evaluation, so check to be absolutely sure this has happened.

DO . . . Bring along a helper to the IEP meeting, if you will feel more comfortable or secure. More and more people are getting special training to act as advocates

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for parents in these new and unfamiliar circumstances. Your helper can rehearse with you ahead of time, explain what will go on and how decisions about the IEP will be reached. Ask members of your local parent organization if they are aware of this kind of help. If you can't find someone trained as an advocate, try to get assistance from another parent who has been through it. Experience is a great teacher, and you can benefit from it.

DO . . . Be as clear as possible in your own mind about what kind of things you believe your child is ready to learn. Talk these over with professionals you trust, and rely on your own knowledge of your child, too. Make a checklist of key items. Does your son need to learn to sit still and listen, instead of interrupting constantly or making inappropriate comments? Does your daughter need to learn how to speak distinctly? Does she need help with self-care skills? Is your teenager getting pre-vocational or job-skill training?

DO . . . Be able to back up your requests for special kinds of help with diagnostic reports, observations and other information from professionals who know your child. If you wish, you may ask to have professionals accompany you to support your point of view. This is your right according to law.

DO . . . Remember—diagnostic reports, important as they are, are not infallible. They don't say *all* there is to be said about a child. Your most important job is to make sure that the others at the conference never forget that you're talking about a real child—not scores attained on a series of psychological tests. Bring up all the real-life information you feel is relevant to a discussion about your son or daughter's educational needs. In the past, there was far too much tendency to rely on reports and records, not to look at the child himself. This is your chance to push for this change in perspective.

DO . . . Be wary of any suggestion to place your child (or leave him) in a classroom that has a label. The old approach was to give children "trainable retarded education" or "blind education" or "physically handicapped education" which more often than not meant inferior education, or none at all. That's what the new law is supposed to stop. The program your child gets should be built on services that relate to strengths and abilities, special problems and learning needs . . . not to his category of disability. If you don't agree that this is what the program does, speak up for your point of view—and make sure that changes are made.

DO . . . Try to understand the issue of "mainstreaming" as fully as possible. The law is based on the right of handicapped children to be part of the world, to learn, work and play alongside their non-handicapped schoolmates. The law's words for it are: educating children in the "least restrictive environment." Somebody coined the word "mainstreaming" to describe this view and the term stuck. Whatever words you use, it makes a big difference in the image that children have of themselves, their confidence and their ability to get along as accepted members of society. This doesn't mean that *every* handicapped child belongs in a regular class. But he *should* be given that chance, if, with sufficient aid and understanding, he can hold his own. And if a child spends all day in a separate class because his need for small classes is so great, he should be given every possible opportunity to join his peers in other school activities. This is an essential part of his education.

DO . . . Take some time to think about how to be assertive without "taking over" or antagonizing people. Meetings about a child's school needs are not intended to be hostile confrontations; they should provide the chance for honest examination of alternatives. One way to keep it successful is to realize you *do* have an essential role to play as an equal-status member of the team—along with educators. Keep calm, listen to what the others have to say, and ask them to extend the same courtesy to you. Your points of view may be new to each other, and you may disagree, but you can learn from one another. If everyone is truly concerned about giving a child the chance he needs to grow and learn, it should be possible to iron out disagreements through persuasion and mutual understanding.

DO . . . Make sure that your child is not excluded from participating in a regular school program because of architectural barriers. This is against the law. Section 504 states very clearly that school facilities must be made accessible and that special adaptations must be made so that services are really available to all students.

STUDY THE FINAL IEP BEFORE GIVING YOUR CONSENT—AND INSIST ON ESSENTIAL SERVICES

DO . . . Have a very complete understanding of the IEP that is produced. A copy of the final IEP should be given to you in writing. Make sure that the education goals that are agreed on are specific and that they accurately reflect decisions that were made at the meeting.

An IEP should *not* contain general goals, like: "Maximize child's potential," but should include clear-cut objectives that can be measured. One objective, for instance, could be: to be able to identify a specific number of words by sight within a certain period of time. Long term goals such as reading at a first grade level should be included, too—so you know where you're going.

An IEP should also say how much time a child is to spend in the mainstream, either in regular classes or extra-curricular activities. Services to be given should be clearly defined. For instance, if speech therapy is in the IEP, how often will it take place? What kinds of

activities will it include? When will it start? How long will it go on? How will progress be charted? If other supportive services, such as transportation or hearing aids are needed, this should be in writing, too.

Check the whole thing carefully—with people who can advise you. The better you know and understand the IEP, the better you will be able to follow your child's progress, monitor the program to see if it is effective, and ask for changes or modifications when necessary.

DO . . . Make sure that appropriate vocational education is in your son or daughter's IEP. This has been a terribly neglected area; insist that work-skill training, on-the-job experience and other skills related to independent living are built into the school program provided for your teenager—as needed. There may not even be a vocational education program for handicapped students in your school system. (You may have to work hard with administrators and teachers to get one started. But speaking up about the need, making sure it's in the IEP, is a first step.)

DO . . . Be firm about things you consider important. Although you don't want to be so rigid that no possible plan could ever get off the ground, you *are* the main protector of your child's interests. If the proposed program segregates your child in a separate classroom all day, and you are convinced that he should have the chance to make it in a regular school activity (at least part of the day), stick to your guns. If a specific classroom or school has been recommended, visit it—to see if it really meets your child's needs. Art, music, school plays, gym, shop are part of the school day for other kids. Your handicapped child should be included. This will require modifications in the way programs are offered—but it can be done!

Due process comes in here. Parents must give their consent to placement of their child. If you feel that an essential part of the program is omitted, is harmful to your child, or is truly inappropriate, you should make your objections known. If the school system is not able to provide the kind of educational program your child must have, it is responsible, by law, for financing an appropriate education in a private facility. This can be a difficult bone of contention, and requires detailed evidence. In all controversies, you must put together documents, reports, letters and other statements (from teachers, doctors, and other specialists who know your child) to support your view. If possible, meet with the school members of the IEP team again to present your side. If you reach a dead end and are unable to convince school officials to change the program or placement, then ask for a due process hearing at this point. While controversial issues are being decided, children must be permitted to remain in their present school setting.

FOLLOW YOUR CHILD'S PROGRAM AND MAKE SURE IT'S WORKING.

DO . . . Get to know the teacher, once your child is placed. Ask when he or she would like to meet with you. Regular conferences are important—to find out how your child is doing, to bring up questions you have, to discuss any possible new efforts at school or at home. A good, trusting relationship between you and the teacher can catch a lot of problems before they get too big to manage.

DO . . . Help teachers and other people in school learn more about handicaps. You can help overcome feelings of fear and pity that come from lack of experience. Share books and articles. If possible, arrange for your child's teacher to visit with your son or daughter before school starts (or after school some day) so he or she has a chance to get a feeling for your child's personal qualities. (The extra boost to their relationship will help them both survive later problems—if they arise.) Offer to talk to other parents in the class—so they in turn can help *their* children accept and understand differences . . . and make friends. You want your child to become independent—but it won't help him to have to deal with unnecessary fear or aggression based on ignorance.

DO . . . Make sure that a formal evaluation of your child's program takes place every year . . . at the very least. If you stay in close touch with the classroom teacher (and other specialists who work with your child), you'll be able to know if changes should take place sooner—and will certainly be able to play a more meaningful part in planning next steps. Making sure that a program continues to be appropriate requires vigilant checking and rechecking . . . to see if school placement is actually encouraging a child's growth.

DO . . . Listen to your child, respect what he's saying. You need to know his reaction to schoolwork, to teachers, to classmates. He may need help getting "toughened up" in the real school world. If you are worried about how things are going . . . again, talk to the teacher, or the school counselor or principal, for advice and suggestions. Keep all your lines of communication open.

BUT PLEASE . . .

DON'T . . . let other people plan for you. If, for instance, you have reason to think that school people met "behind the scenes" to agree on the IEP, effectively keeping you out of the act, you have grounds to complain loudly. Some school administrators have had nothing but difficult experiences with parents and they freeze at the thought of working with them. (It works the other way around, too. You may have had so many frustrating or intimidating experiences that you don't want to try again. Please do.) You and the school *can* work together. Don't let the potential for a new creative process die by default.

DON'T . . . settle for poor or inadequate services. If you find that your child's problems are ignored, that special resource teachers or educational materials don't exist, that your child is deprived of assistance he

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needs to adjust to a mainstreamed classroom in which he has been placed . . . take action. Demand changes in keeping with the promise of an appropriate program.

Due process comes in here. If your efforts to work with your child's teacher, principal or school administrators fail, you have a right to request a due process hearing at this point in order to protest your child's placement.

DON'T . . . let yourself feel put down at the meetings held to discuss, plan or evaluate your child's program. It may sound scary at first, but it really doesn't have to be. When professionals use language you don't understand, feel free to ask for explanations. Remember that you are all there for the same purpose: to work out what's best for your child . . . to pinpoint his needs and to make decisions on what resources, services and special programs he needs in order to learn. You can make a valuable contribution by raising questions when ideas and recommendations don't seem to make sense.

DON'T . . . forget that, no matter how important every educational service provided to your child may be, he is a young, responsive, growing individual, with human needs to laugh, play, make friends—not a composite of diagnosed needs. The brightness of social success means as much as academic progress (sometimes, it can mean even more). This side of life can be overlooked in conscientious efforts to improve learning skills. Your handicapped child is a person—and the purpose of all these efforts is to help him use his own strengths to become the most fulfilled person he can be. That's why it's so important to give each kid as much chance as possible to join the mainstream and to be part of the fun activities of school.

DON'T . . . try to do this all alone. Join with other parents in an organization for handicapped individuals, or the PTA, to learn all you can about new federal and state laws, the way your own school system works, how to stick up for your rights. There's so much to do! You're not the only one who needs help. Find your allies—and work together. If teaching programs for handicapped children are below standard, and none of your efforts to bring about improvement have worked, you will be far more effective if you become part of an organized group. You can add strength to a broader effort to implement and strengthen existing laws, to push for increased funding by state legislatures, to awaken the rest of the community to the rights of handicapped children.

The work presented herein was performed pursuant to a contract with the Bureau of Education for the Handicapped, U.S. Office of Education.

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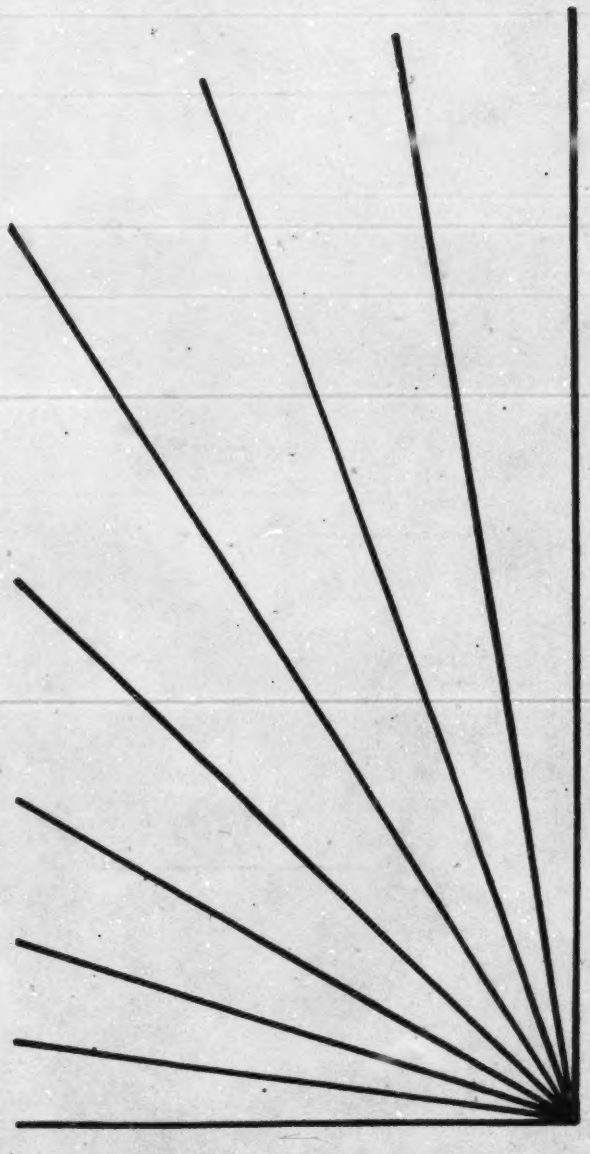
Guidelines

for the Representation of Exceptional Persons in Educational Material



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4/77

Educational materials have an enormous effect on the formation and reinforcement of behavior and attitudes. A substantial representation of persons with exceptionalities has been omitted from educational materials or has been stereotyped because of a lack of understanding about exceptional persons. Today, more opportunities are available for persons with exceptionalities to participate in the mainstream of society.

The Consortium for Appropriate Representation of Exceptional Persons in Educational Material recognizes that few educational materials have adequately portrayed persons with exceptionalities. This situation needs to be corrected because:

- There are approximately eight million persons in this country with exceptionalities.
- Despite periodic articles or news coverage about persons with exceptionalities, the vast majority are not represented at all.
- Many people do not understand or know how to relate to a person with an exceptionality as a person first and a person with an exceptionality second.
- Probably less than one percent of educational materials represents persons with exceptionalities.

Because of these conditions, the Consortium proposes the Guidelines to foster the positive, fair, and balanced representation of exceptional persons in print and nonprint educational materials. The Guidelines are not considered to be all inclusive, but are intended to assist publishers/producers in developing a sensitivity to the manner in which persons with exceptionalities need to be represented.

Converting to positive, fair, and balanced representation will not be easy, any more than it was easy to convert to balanced and appropriate sex, ethnic, or social representation. Publishers and producers with philosophical and practical problems in implementing the Guidelines are encouraged to contact the Consortium through the address below for more information. All publishers and producers are urged to provide feedback that can help refine the present guidelines.

Write to:

Angele Thomas
EXCEPTIONAL CHILDREN
Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
Telephone: (800) 336-3728

Guidelines

1 **In print and nonprint educational materials, ten percent of the contents should include or represent children or adults with an exceptionality.**

Do your educational materials reflect the fact that ten to fifteen percent of the population is composed of persons with exceptionalities?

If your materials do represent exceptional persons, have you limited the exceptionalities to deaf, blind, or physically handicapped?

Have any of your materials included the following conditions?

Behavioral Problems
Giftedness
Hearing Impairments
Learning Disabilities
Mental Retardation
Multiple Handicaps
Neurological Problems
Physical Handicaps
Serious Emotional Problems

2 **Representation of persons with exceptionalities should be included in materials at all levels (early childhood through adult) and in all areas of study.**

Do all of your efforts at representation focus on the elementary education market?

Have you made an effort to include persons with exceptionalities in such curriculum areas as:

Career Education
Guidance
Health Studies
Language Arts
Mathematics
Physical Education
Science
Social Studies
Vocational Education

3 **The representation of persons with exceptionalities should be accurate and free from stereotypes.**

Are you aware that each exceptionality has varying degrees of severity?

Have you represented the deaf as dumb; the blind as pitiful; the intellectual as bookwormish; the mentally retarded person as poorly groomed, as unkempt, or as the "fool"?

Have you stereotyped persons with exceptionalities as "the blind beggar," "the disfigured villain," or "the insane criminal"?

4 **Persons with exceptionalities should be shown in the least restrictive environment. They should be shown participating in activities in a manner that will include them as part of society.**

Are all deaf persons shown only in the company of other deaf persons?

Are all retarded persons shown in institutions, or going places only in groups?

Does your material reflect the idea that persons with exceptionalities cannot function in the mainstream of society?

Does your material foster the attitude of "one of them" as opposed to "one of us"?

5 **In describing persons with exceptionalities, the language used should be nondiscriminatory and free from value judgments.**

Do you avoid the use of clichés and phrases that cast aspersions on persons with exceptionalities, such as: village idiot, deaf and dumb, spastic, egghead, four eyes, bookworm, gimp, retard, lamebrain?

Do your materials reflect attitudes of pity or condescension, such as "poor little cripple"?

6 **Persons with exceptionalities and persons without exceptionalities should be shown interacting in ways that are mutually beneficial.**

Are the persons with exceptionalities always shown being helped by others rather than vice versa?

Have your materials shown positive interpersonal relationships between persons with and without exceptionalities?

Do your materials show how persons with and without exceptionalities can communicate naturally, without embarassment or awkwardness?

7 **Materials should provide a variety of appropriate role models of persons with exceptionalities.**

Have you explored the full range of jobs that persons with exceptionalities do perform or have you limited yourself to a narrow range of occupations?

Have you ever depicted persons with exceptionalities as parents, community leaders, or business executives?

Do you depict the typical achiever, as well as the super achiever as a role model?

8 **Emphasis should be on uniqueness and worth of all persons, rather than on the differences between persons with and without exceptionalities.**

Does your use of labels set persons with exceptionalities unnecessarily apart from others, in a manner such as "Sally, Anne, and Robert, their blind friend"?

Do your materials foster the appreciation of similarities between persons with and without exceptionalities?

9 **Tokenism should be avoided in the representation of persons with exceptionalities.**

Is your idea of representation one child with a hearing aid in a full classroom?

Do you use persons with actual exceptionalities in your materials?

Do you attempt to go beyond the superficial or obvious in depicting the exceptionalities?

HOW CAN YOU APPLY THE GUIDELINES?

You can:

Show a teacher in a wheelchair in a classroom or wheelchair basketball, and other wheelchair sports.

Present sign language in a communications course as an alternative method of communicating.

Show persons with cerebral palsy bowling in a public bowling alley.

Create math problems using insulin measurement.

Explain workings of the hearing aid as a science or electronics project.

Show a blind person playing a musical instrument.

Use artificial limbs and other prosthetic devices for illustrations in areas of physics, engineering, physical education, hygiene.

Show the design of a community or building totally accessible to persons with handicaps.

Show persons with and without exceptionalities enjoying nature trails designed for public use.

Show a person with paraplegia driving a car.

Describe how a person with dyslexia can work in an office.

Show persons with speech disorders working in radio stations, writing scripts, or scheduling programs.

Show persons with exceptionalities in a variety of occupations such as: typesetters, lithographers, truck drivers, industrial workers, artists, authors, public servants.

NOTE: All exceptionalities are not easy to depict; there are subtleties and considerations that require responsible and sensitive treatment to portray them adequately. The examples listed above are meant to stimulate thought in the application of these guidelines. For definitions of handicapping conditions and related information, refer to the Rehabilitation Amendments Act of 1973 (Public Law 93-112), the Rehabilitation Amendments of 1974 (Public Law 93-516), the Education of All Handicapped Children Act of 1975 (Public Law 94-142), and the regulations thereunder.

The Council for Exceptional Children may be contacted for more information about those organizations that serve specific exceptionalities and that can provide more information on how to represent persons with exceptionalities.

ABOUT THE CONSORTIUM

In April, 1976, the Delegate Assembly of the Council for Exceptional Children (CEC) passed a resolution calling for action to develop guidelines for the constructive treatment of persons with exceptionalities in educational materials. CEC enlisted the assistance of the National Center on Educational Media and Materials for the Handicapped (NCEMMH) and faculty members from the University of Pittsburgh.

Efforts of these three groups led to the establishment of The Consortium for Appropriate Representation of Exceptional Persons in Educational Material. Members represent NCEMMH, CEC, the Area Learning Resource Centers, the fields of special education and curriculum development, the American Association of Publishers, the White House Conference on Handicapped Individuals, the President's Committee on the Employment of the Handicapped, the National Audio-Visual Association, and the Association of Media Producers.

Representation of persons with exceptionalities in educational material appears to exhibit many of the problems evidenced in studies of the treatment of sex roles and of various ethnic and racial groups in similar materials. A growing concern for the fair and adequate representation of persons with exceptionalities, and attention in the education profession to mainstreaming, indicate the need for similar guidelines regarding the treatment of these persons in educational material.

Public Law 94-142, Education for All Handicapped Children Act of 1975, gives a special immediacy to this need. Signed into law November 29, 1975, the law mandates a zero reject policy with regard to the education of persons with exceptionalities. Further, the concept of least restrictive alternatives, as part of the law, reflects the view that the best education for all students is accomplished in an environment that will facilitate the learner's ability to participate in our society. Therefore, it can be expected that more students will have increasing contact with students exhibiting marked human variation in physical, mental, and behavioral attributes in the everyday learning environment.

The intention of these guidelines is to assure that print and nonprint educational materials reflect a positive, fair, and balanced representation of persons with exceptionalities. It is expected that such representation will help all persons with and without exceptionalities to live their lives with a realistic and empathetic understanding of individual differences and abilities.

The guidelines rest on the assumption of the overall similarity of human wants and needs, and the recognition that each individual is unique.